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**An ecological exploration of the barriers and facilitators to
cervical cancer screening and HPV self-sampling acceptability
amongst Moroccan and Pakistani women in Spain**

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Statement of own work

I, Jone Garcia Lurgain, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed: Jone G. Lurgain

Date: 15 January 2025

Abstract

Despite free and universal access to healthcare in Spain, cervical cancer (CC) screening disparities persist. Moroccan women rank among the immigrant groups with lowest rates of CC screening uptake in Spain and there is strong evidence in other European countries that Pakistani women are also an under-screened immigrant group. Human papillomavirus (HPV) self-sampling has been proposed as a promising strategy to increase screening uptake amongst not-screened or under-screened women. Although studies indicate that women are generally receptive to this self-collection method, results may not be generalizable to all ethnic groups and settings. My PhD research, therefore, seeks to better understand barriers and facilitators to CC screening and, specifically, to assess HPV self-sampling acceptability among these two immigrant groups.

Using a qualitative-driven mixed-methods approach, this study combined focus groups and interviews with immigrant women and healthcare providers to explore individual, interpersonal and health system barriers and facilitators to CC screening. Second, an egocentric social network analysis of 22 participants was undertaken to examine the role of women's social networks on their CC screening behaviours. And finally, all participants (N=73) were invited to use two HPV self-sampling devices and complete socio-demographic and acceptability questionnaires. Thematic content analysis and descriptive statistics were performed.

Acknowledging the differences between Moroccan and Pakistani communities (i.e. with regard to culture and migration history), this research identifies common barriers and facilitators to CC screening among both groups of women in Catalonia, Spain. At individual level, cultural and religious beliefs seemed to influence their self-care and preventive health behaviours; inadequate information about CC and HPV screening, and low risk perception towards HPV infection also undermined women's participation in screening, and language limitations were another significant barrier. At the interpersonal level, by analysing women's social networks, my study demonstrates the positive role played by the verbal cultures of these two communities and immigrant peer relationships in changing normative beliefs and attitudes regarding CC prevention; male partners also appeared to play conflicting roles as health promoters and as barriers to CC screening. At a health system level, the research describes the communication challenges between immigrant patients and healthcare providers and urges an action plan to improve cultural competence throughout the Catalan health system. Finally, while HPV self-sampling acceptability rates differed between Moroccan and Pakistani women, both expressed their preference for clinician-based screening, and showed low self-efficacy to perform the self-sampling correctly.

The overall findings of this thesis have significant implications for how CC screening disparities are understood and addressed in communities with different cultural backgrounds. This research reinforces the importance of culture in health behaviours and propose leveraging social network approaches to design more effective interventions. In this specific case, peer-based participatory interventions with linguistically and culturally sensitive educational materials seem to be the most suitable approach to foster confidence among these two communities, and increase their participation in CC screening.

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This research took place in Catalonia, Spain, and it was embedded in a broader organised population-based cervical cancer screening program, implemented by the Catalan Institute of Oncology (ICO) in Barcelona. I thank Paula Peremiquel Trillas and Laia Bruni for supporting my PhD proposal and sharing valuable knowledge on cervical cancer screening programmes. They hosted me in their research centre, gave me the opportunity to undertake interesting courses and provided the necessary contacts to conduct the data collection, such as the community health team at the Drassanes International Health Unit - Vall d'Hebron Hospital. Thank you to the fieldwork team: Hakima Ouaraab Essadek, Sumaira Malik Hameed and, especially, Khadija Mellouki and Andleed Sarif, who were excellent research assistants and an important support (professional and emotional) during the data collection period. I also thank Valentina Rangel-Sarmiento (ICO), Chaima Zoljami (medical student) and Iman El Messaoudi (interpreter) for their translation and transcription support.

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List of abbreviations

CC – Cervical cancer

CIN - Cervical intraepithelial neoplasia

CBPR – Community-based participatory research

CBSD – Community-based system dynamics

CHW – Community health workers

ESRC – Economic Social Research Council

EU – European Union

FGD – Focus group discussion

RGPD – General Data Protection Regulation

HBM – Health Belief Model

HDI – Human Development Index

HIC – High income countries

HIV - Human immunodeficiency virus

HPV – Human Papillomavirus

HrHPV – High risk Human Papillomavirus

H-SIL – High-grade squamous intraepithelial lesions

HCD – Human-centred design

IARC – International Agency for Research on Cancer

ICO – Catalan Institute of Oncology

ILO – International Labour Organization

IOM – International Organization for Migration

KII – Key informant interview

LMIC – Low- and middle- income countries

LSHTM – London School of Hygiene and Tropical Medicine

L-SIL - Low-grade squamous intraepithelial lesions

NGO – Non-Governmental organisations

PCR – Polymerase chain reaction

PHC – Primary healthcare

PPI – Patient & Public Involvement

RA – Research assistant

RCT – Randomized controlled trial

SEM – Socioecological model

SMS – Short-message service

SNA – Social network analysis

SOP – Standard Operational Procedures

SRH – Sexual and reproductive health

SRHR – Sexual and reproductive health and rights

SSI – Semi-structured interview

STI – Sexually transmitted infection

TPB – Theory of Planned Behaviour

TRA – Theory of Reason Action

UCL – University College London

UHC – Universal healthcare

VIA - Visual inspection with acetic acid

WHO – World Health Organization

Chapter 1 Introduction

The overall aim of this thesis is to inform the adaptation of organised population-based cervical cancer (CC) screening programmes and/or the design of future interventions to increase screening uptake among immigrant populations and reduce health disparities in CC prevention. Using the case of Moroccan and Pakistani immigrant women living in Catalonia, Spain, this qualitative-driven mixed-methods study was designed with a dual purpose: first, to explore barriers and facilitators to CC screening using an ecological analysis approach, and second, to specifically assess acceptability of HPV self-sampling as a primary sample collection method for CC screening among these two groups of women.

In this chapter, I introduce my thesis with a brief description of the persistent CC screening disparities among immigrant women across Europe and in Catalonia, Spain (1.1). I then provide explanations of key terminology used throughout the thesis and important conceptual considerations (1.2) and my motivations and formulation of the study (1.3). Next, I describe the funding and collaborating partners of the study (1.4), aim and objectives (1.5), research questions (1.6) and structure of the thesis (1.7). Finally, I explain the relevance of the study (1.8) and present the contribution of the author (1.9), and dissemination of findings (1.10).

1.1 Cervical cancer screening disparities

CC is the fourth most common cancer among women and the fourth leading cause of cancer death in women worldwide, with an incidence rate of 13.3 per 100,000 women-years and a mortality rate of 7.2 per 100,000 women-years (Singh et al., 2023; Ferlay et al., 2021; Sung et al., 2021). Globally, CC affects over 662,000 women and causes nearly 350,000 deaths every year (WHO, 2024). The vast majority of CC cases, around 85%, occur in low- and middle- income countries (LMIC) (Ferlay et al., 2022). Although it is a preventable disease (Bouvard et al., 2021), CC remains a significant global public health problem primarily due to persistent disparities across countries and populations in terms of access to primary (vaccination) and secondary (screening) prevention programmes and treatments (Ginsburgh et al., 2017).

1.1.1 The European context

Over the past 50 years, the incidence and death rates from CC have declined considerably in high-income countries (HIC) and much of this reduction has been attributed to the availability of screening programmes (Kitchener, Castle and Cox, 2006). In Europe, well-organised population-based screening programmes have reduced mortality by 80% or more among screened women (Jansen et al.,

2020; Arbyn et al., 2009). However, there is still a significant number of eligible women who do not benefit from screening services, especially among socioeconomic disadvantage groups, such as immigrants from non-Western countries (Rosato et al., 2023; Brzoska, Aksakal and Yilmaz-Aslan, 2020; Hertzum-Larsen et al., 2019; Idehen et al., 2018; Rosano et al., 2017), where the rollout of screening is very low: only 34 million (9%) of 397 million women aged 30-49 years living in LMICs had been screened ever in lifetime, compared with 133 million (84%) of 158 million women in HICs (Bruni et al., 2022), and the burden associated with the disease is the highest as mentioned above (Singh et al., 2023).

A recent systematic review and meta-analysis (including mainly studies conducted in Europe) (Rosato et al., 2023) revealed that the mean participation in CC screening was considerably lower for immigrant populations (19.1% versus 62.3% in women born in the country) and that immigrant women had a 46% lower chance of participating in CC screening compared to non-migrant women. By regions of origin, the lowest probability for screening was observed for women coming from Sub-Saharan and North Africa, and Asia (Rosato et al., 2023). These low screening participation rates increase the risk of late diagnosis and treatment among these populations (Collatuzo et al., 2023; Azerkan et al., 2012; Arnold, Razum and Coebergh, 2010) and subsequent CC mortality risks (Hallowell et al., 2019). Increasing screening uptake among immigrants is, therefore, imperative and urgent for the improvement of health outcomes of these populations, the reduction of health disparities and progress towards the global elimination of CC.

Screening for CC began with the Papanicolaou (Pap) test/smear (or cervical cytology) well before the link between Human papillomavirus (HPV) infection and CC was established in the 80s (De Villiers et al., 1987). This routine screening test, discovered by the Greek physician Georgios Nikolaou Papanicolaou (Papanicolau and Traut, 1997), allowed for early detection of precancerous cells and it was adopted widely, although the procedure - a visual examination of the smears under the microscope - was time consuming, expensive and required specialised training as a cytotechnologist (Bengtsson and Malm, 2014). Newer screening tests have been introduced in the last 15 years, such as visual inspection with acetic acid (VIA) and molecular tests, mainly high-risk HPV (hrHPV) DNA-based tests, which check for the presence of the hrHPV genotypes (i.e. 16 and 18), the causal agents in CC. These latter tests have been found to be suitable for use in all settings (WHO, 2021), allowed the use of self-sampling methods (Serrano et al., 2022) and proved to be more effective than the traditional Pap smear in reducing cervical (pre)cancer incidence (Koliopoulos et al., 2017; Ronco et al., 2014). In a recent review of the CC screening programmes worldwide, Bruni et al. (2022) found that cytology continued to be the primary screening test in 109 (78%) of 139 countries examined and 48 (35%) already recommended HPV-based screening, but most (at least 21 countries) were still transitioning from cytology (Pap smear) to HPV as the main test.

Along with the type of test used, the sufficient coverage of the target population is a crucial factor influencing the effectiveness of a CC screening programme, together with an adequate diagnosis, follow-up and management of positive results. Evidence indicates that CC screening is more effective when it is undertaken under an organised population-based programme than opportunistic screening (Ferroni et al., 2012; Salo et al., 2014; Serraino et al., 2015). In an organised population-based programme, women in the target population are identified and systematically invited (e.g., via SMS, a letter) to receive CC screening. By contrast, opportunistic screening depends on the initiative of the patient (or doctor), so the screening coverage depends on the frequency of visits to a doctor. Hence, organised population-based screening programmes ensure greater coverage and cost-effectiveness compared with opportunistic screening, as long as there are good response rates. Many countries, especially those with limited resources, face however important challenges to implement organised population-based screening programmes, maintaining CC screening disparities.

In Europe, the European Union (EU) guidelines recommend the introduction of HPV testing as a primary screening strategy at the age of 30 with a five-year interval (Maver and Poljak, 2020; Von Karsa et al., 2015) and using organised population-based screening programmes (Arbyn et al., 2008, 2010). However, EU countries are not obligated to follow EU guidelines, as healthcare is the exclusive responsibility of each member state. In those countries with organised CC screening, participation is offered equally to both women born in the country and immigrant women; however, as the above studies shown, some women, such as immigrants from non-Western countries, show lower participation rates.

1.1.2 The Spanish context

The number of immigrants in Spain has been growing over the past two decades, but the highest immigration flows occurred at the turn of the millennium when the foreign-born population increased from 2.5% in 2001 to 13.5% in 2011 (Ronda-Perex et al., 2014). Since then, the foreign population has stabilized at around 13-14% of the total population (INE, 2024). Catalonia, in north-eastern Spain, where this research was conducted, is one of the regions that witnessed the largest influx of immigrants and as of 2024, its foreign population has reached 1.2 million (16.3% of the Catalan population). The largest non-EU majority groups, excluding immigrants from Latin America, come from Morocco (18.5% of the migrant population), China (4.9%) and Pakistan (4.3%) (IDESCAT, 2024).

The Spanish health care system is largely tax-financed and is based on a principle of free and universal healthcare (UHC) access for all registered residents (BOE, 1986). The right to healthcare,

with the same conditions enjoyed by citizens born in the country, is recognized for registered foreigners (with or without a residency permit) (BOE, 2000). This includes access to preventive healthcare, such as CC screening programmes, which are regionally organised (or decentralised) and, unlike in other European countries, such as Italy, Netherlands or Sweden, they have been mostly opportunistic, in part due to the traditionally low incidence and mortality rates of CC in Spain (Cervantes-Amat et al., 2015) (see CC rates in the Background, Chapter 2).

In terms of CC screening coverage, in Spain 83% women have been screened for CC in the last 5 years (WHO, 2021, page 164). However, as in other European countries, studies have reported disparities in screening among immigrant populations. For instance, a cross-sectional study based on the Spain's National Health Survey 2006 (Pon-Vigues et al., 2011), showed a lower percentage of regular CC screening among immigrant women from low income countries compared to women born in Spain (56% vs 65%). A more recent study using the National Health Survey of Spain 2012 demonstrated that the gap between immigrant and non-migrant women remained the same, although both groups increased coverage (62% vs 71%) (Barrera-Castillo et al., 2020).

This thesis presents the case of Moroccan and Pakistani immigrant women living in Catalonia, Spain. The Moroccan community is the largest group of foreign immigrants - excluding Latin American immigrants - in Catalonia, representing 3% of the total population, and nearly half of them are women (IDESCAT, 2024). Although the evidence on CC screening coverage among Moroccan immigrant women is scanty in Spain, earlier studies indicated that Moroccan women rank among the immigrant groups with lowest rates of cervical and breast cancer screening uptake (Sanz-Barbero, Regidor and Galindo, 2011; Pons-Vigués et al., 2012; March et al., 2018). Lower use of cytology was reported by women from Africa (20.8%), including those of Moroccan origin, and the probability of having undergone a cytology was 0.47 (95% CI 0.33;0.67) times less among African immigrant populations in relation to Spain-born women (Sanz-Barbero, Regidor and Galindo, 2011). More specifically, in the study conducted by Pons-Vigués et al. (2012), Maghrebi women perceived the most barriers to breast cancer screening, specifically, they scored 14.0 points higher than women born in Spain on the 'barriers' scale of the study.

The Pakistani community, although a relatively small group of foreign immigrants in Spain, has experienced a rapid 72% increase in population between 2010 and 2020 (INE, 2024). More than half of the total Pakistani population residing in Spain lives in Catalonia (56%), particularly in Barcelona and its neighbouring municipalities (IDESCAT, 2024; INE, 2024). Although no studies in Spain have specifically examined Pakistani women's CC screening rates, there is evidence suggesting that Pakistani women are also an under-screened immigrant group (Qureshi et al., 2019; Lofters and Lobb,

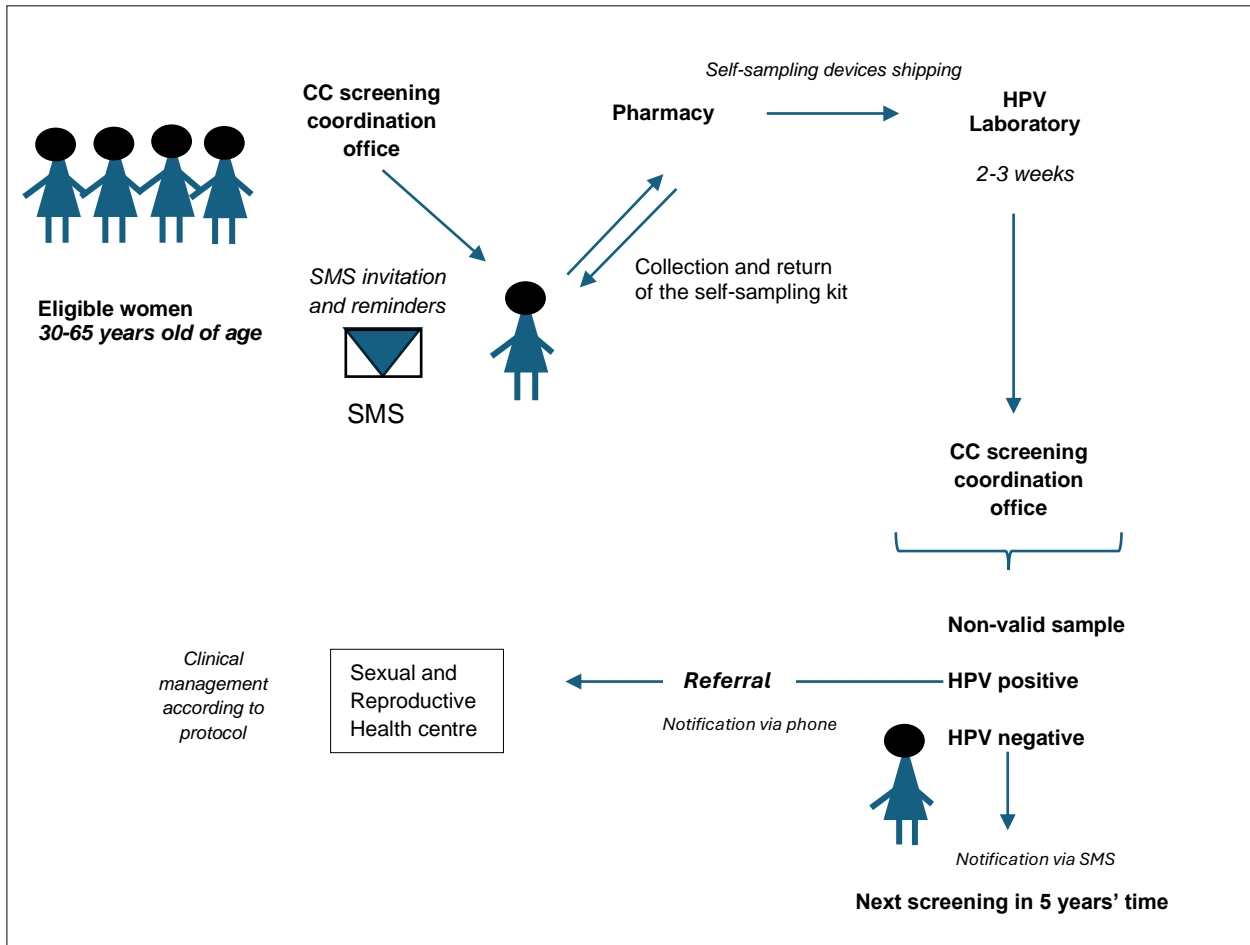
2015; Szarewski et al., 2009). For instance, Qureshi et al. (2019) reported that Somali and Pakistani women have the lowest participation rates of CC screening in Norway.

Given the evidence on CC screening coverage amongst immigrants is not sufficient in some European countries, such as Spain, it is important to pay also attention to the availability of screening services in immigrant women's countries, as well as their knowledge and screening behaviours back in their own countries, as these may persist once they settled in the host country. In the case of Moroccan and Pakistani women, studies showed that women are often diagnosed at advanced stages in these two countries and that the CC screening coverage rates in Pakistan and Morocco are as low as 2% and 8%, respectively, as I explain later in the Background section.

The lack of organised population-based screening programmes in Spain has been considered one of the main drivers for these screening disparities (Espinass et al., 2011). Responding to the European guidelines (Anttila et al., 2015) and the Global strategy for CC elimination led by the World Health Organisation (WHO, 2020), in April 2019, the Ministry of Health issued official screening guidelines for CC and urged all Spanish regions to transition from opportunistic to organised CC screening programmes, as well as using HPV test as primary screening. The guidelines recommend cytology-based screening every three years from 25 to 30 years of age, followed by HPV-based screening every five years from 35 to 65 years of age (BOE, 2019).

In this transitional context, Catalonia is currently shifting from opportunistic to an organised population-based screening programme (GENCAT/Salut, 2023) and it is one of the very few regions in Spain introducing HPV-based self-sampling as a primary sample collection method for CC screening. Specifically, the new Catalan screening guidelines recommend HPV-based self-sampling to all women between the ages of 30 and 65, whereas cytology is still offered to younger women (25-30 years old). In addition to home-based HPV self-sampling, the possibility to request clinician-based screening is also available to women who prefer it or cannot perform self-sampling without assistance. The proposed organised CC screening programme is coordinated by screening technical offices that invite eligible women to collect self-sample devices in a near-by pharmacy through a short-message service (SMS). Pharmacies also collect and deliver the samples to the laboratories. An SMS is sent to inform women about the availability of the results in the Catalan digital health App (La Meva Salut) once the result is negative and the screening process is repeated in five years. If a positive result is obtained, a midwife communicates the result via phone call and gives the appointment for triage (Catalan Institute of Oncology, 2024) (see Figure 1).

Figure 1 Algorithm for HPV-based cervical cancer screening using self-sampling in Catalonia, Spain.



1.2 Key terminology and conceptual considerations

1.2.1 Migration-related terms

Definition of migrants

Migration terminology (see glossary in Table 1) can be confusing and it is often misused in the public sphere, but also by migration health researchers (The Migration Observatory, 2024). This is in part due to the lack of consensus on a single legal definition of a ‘migrant’ under international law (IRC, 2024). The use of the term ‘migrant’ is extremely loose as it can include internal and foreign-born migrants, such as economic migrants (international, rural-to-urban), internally displaced people, refugees, asylum seekers. The majority of migrants in the world are economic migrants: those who leave their country of origin in order to seek material improvement in their livelihood (EU Migration and Home Affairs, 2024). According to the latest estimates (ILO, 2021), there are 169 million international migrant workers globally, which represent around 69% of the world’s international migrant population, but the proportion of refugees, asylum seekers and displaced people are at their highest levels, representing around 10% of all migrants who move between countries (Abubakar et al., 2018). They may migrate due to persecution based on their ethnicity, religion, race, politics, or culture. War, conflict, government persecution, or the risk of these can also be major factors of migration, alongside natural disasters and climate change (European Parliament, 2024).

For the purpose of this thesis, I consider a migrant to be *‘any person who is moving or has moved across an international border or within a State away from his/her habitual place of residence, regardless of the person’s legal status, whether the movement is voluntary or involuntary, what the causes for the movement are and what the length of the stay is’* (IOM, 2019).

The term ‘migrant’ is often used interchangeably with the term ‘immigrant’ despite having different definitions. While ‘immigrants’ are people who are, or intend to be, settled in their new country, which effectively becomes their usual residence, ‘migrants’ are considered those who are temporarily residents (IOM, 2024, The Migration Observatory, 2024). In terms of who counts as international migrant when interpreting datasets, some studies define migrants as ‘foreign-born’ (country of birth) and others, as ‘foreign nationals’ (nationality) (The Migration Observatory, 2024). Similarly, when it comes to making comparisons, the literature also uses different terms to refer to the host country population, such as ‘nationals’ (nationality regardless their country of birth) or ‘natives’ (born in the country).

The migration health literature also distinguishes between first-, second- (also referred to as 1.5) and third- generations of immigrants. According to the glossary proposed by the EU Migration and Home Affairs (2024), a second-generation immigrant is a person who was born and is residing in a country that at least one of their parents previously entered as a migrant and settled as a resident (first-generation immigrant), whereas the third-generation are the grandchildren of immigrants. However, this classification is for research purposes, as in real terms, both ‘second- and third-generation immigrants’ are not immigrants, but native (born in the country).

The study population in this thesis is first-generation immigrants (foreign-born) regardless of their citizenship status, and specifically, women who were born in Morocco or Pakistan and migrated to Spain with the intention of living there permanently. In my study sample, the reason for which the majority of the participants migrated to Spain was family reunification, which is the right of non-nationals to enter into and reside in a country where their family members reside lawfully or of which they have the nationality in order to preserve the family unit (IOM, 2024). With regards to the host country population, in this thesis I refer to women born in Spain and, specifically, in the Catalonia region, rather than women with Spanish nationality who might have been born abroad.

Uses and misuses of race and ethnicity

Migration patterns have facilitated increasingly multi-racial and ethnically pluralistic societies (Richmond, 1978), leading to categorisation of individuals by race and ethnicity in clinical, epidemiologic and public health research, particularly to target health disparities (Erayil et al., 2021; Burchard et al., 2003; Risch et al., 2002; Lin and Kelsey, 2000). The concepts of race and ethnicity have evolved over time and there is no consensus on their definitions (see glossary in Table 1). Both constructs have been used interchangeably (e.g. racial/ethnic groups) in data collection in healthcare, but in recent years a reassessment of the race/ethnicity categories is urged. As Erayil et al. (2021) explain, the broad race/ethnicity categories (e.g. ‘Black’, ‘White’, ‘Asian’) to which individuals are assigned fail to identify differential risks between these very distinct groups. For instance, people of Middle Eastern or North African heritage are currently considered ‘white’. However, the disparities they suffer, the racism they encounter, and the health challenges they face, are more akin to those of other people of colour (Abuelezam, El-Sayed, Galea, 2018). Therefore, addressing health inequities requires data that can more precisely identify the different groups and their needs to better inform public health organisations, health systems and clinical providers, and design more effective interventions, as well as more equitable allocation of resources (Erayil et al., 2021).

Acknowledging the existence of different ethnolinguistic groups within Morocco (e.g. Amazighs (Berbers), Riffians) and Pakistan (e.g. Punjabis, Pashtuns), I refer throughout the thesis to the generic

term ‘immigrant’ women from Morocco and Pakistan, rather than racial/ethnic minority groups, reflecting the complex intersectionality of migration, race/ethnicity, country of origin, religion (Muslim), gender and language.

Table 1 Glossary of migration-related terminology.

Term	Definition
Migrants	Any person who is moving or has moved across an international border or within a State away from his/her habitual place of residence, regardless of the person’s legal status, whether the movement is voluntary or involuntary, what the causes for the movement are and what the length of the stay is. (IOM, 2019).
Immigrants	People who are, or intend to be, settled in their new country, which effectively becomes their usual residence, whereas migrants are considered those who are temporarily residents (IOM, 2024).
First-, second-, third-generation migrants	<ul style="list-style-type: none"> • First-generation migrant is a person who entered in a country as a migrant and settled as a resident. • Second-generation migrant is a person who was born and is residing in a country that at least one of their parents previously entered as a migrant and settled as a resident. • Third-generation migrants are the grandchildren of immigrants. (IOM, 2024)
Country of birth	Country of birth refers to the country in which a person is born. (IOM, 2024)
Country of origin	In the migration context, country of origin refers to a country of nationality or of former habitual residence of a person or group of persons who have migrated abroad, irrespective of whether they migrate regularly or irregularly (IOM, 2019).
Race	Persons who are relatively homogeneous with respect to biological inheritance (Last, 1995, p. 139).
Ethnicity	<ul style="list-style-type: none"> • Ethnic group is a social group characterized by a distinctive social and cultural tradition, maintained within the group from generation to generation, a common history and origin, and a sense of identification with the group. Members of the group have distinctive features in their way of life, shared experiences and often a common genetic heritage. These features may be reflected in their health and disease experience (Last, 1995, p.57). • Ethnicity refers to the social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including language, diet, religion, ancestry and physical features traditionally associated with race. Ethnicity is different from country of origin, since many countries include more than one ethnic group (Bhopal, 2004).

Migration as a social determinant of health

Social determinants of health are often associated with living and working conditions, physical and social environment, education, gender, as well as degrees of social cohesion and integration.

Migration is also considered another social determinant of health. Although migrants have different backgrounds and situations, and their migration experiences may vary significantly, migration itself adds a particular dimension to social determinants of health, as being a migrant can make people more vulnerable to negative influences to their health (Davies, Basten and Frattini, 2009).

The migration process, reasons for migration, the mode of travel, length of stay and the migrant's individual characteristics: language skills, religion, race, ethnicity, and legal status can all impact a migrant's health through different mechanisms, such as social exclusion, lack of social support, financial hardship, housing insecurity, unemployment, racism, which impact their access to healthcare and health outcomes (Castañeda et al., 2015; Davies, Basten and Frattini, 2009).

Culture and migrant health

Individuals' cultural values and practices can impact on health behaviours and health outcomes (Iwelunmor, Newsome and Airhihenbuwa, 2013). However, failure to recognise the intersection of culture with other structural and societal factors creates and compounds poor health outcomes, multiplying financial, intellectual and humanitarian costs (Napier et al., 2014). Using this intersectional lens, for the purpose of this thesis, I define 'culture' in relation to health not only as a set of habits and beliefs socially transmitted within a group of people who share the same racial heritage or ethnic identity, but as an ecological and dynamic system shaped by the environment, political history, religion, language, and social structures (Hammond, 1978; Bronfenbrenner, 1994, Kawaga-Singer et al., 2010, 2012).

The above definition of 'culture' helps to understand that not all members of a group that share languages, practices and overt expressions of belief automatically share a given value, not local ideas can be readily translated across or even within a given group (Napier et al., 2013). This is especially relevant when addressing the influence of culture on migrants' health behaviours and health outcomes, as migrants' culture can interact or be influenced by the host country culture and change over time. As Kawaga-Singer et al. (2010, 2012) note, when members of a cultural group migrate, their cultural values and beliefs may change over time due to the adoption of practices or technologies from other cultural groups in the host country. Failure to acknowledge the effects of accommodation

to other cultures and the fluidity of cultural beliefs and practices may lead to erroneous presuppositions and stereotyping patients and their families from particular cultural groups.

For example, a study conducted in France demonstrated how immigrants' health status tended to deteriorate with duration of stay which may be due to discrimination; poor employment conditions; differences in access and use of healthcare services. The study suggested that this "migrant health deficit effect" (in comparison with natives) was less pronounced for second-generation migrants (Lebano et al., 2020). This reflects that although migrants transmit their cultural values and practices to their children, these second-generation migrants (born in the host country) may differ in attitudes, beliefs, language skills and experiences due to the adoption of the host country's values and culture, resulting in better access to healthcare and health outcomes.

Religious beliefs and practices have also been considered an important determinant of health, including among Muslim migrants in Western countries. Studies have shown both positive and negative influences of the Muslim faith on health behaviours and health outcomes (Padela et al., 2018; Ahaddour and Broeckeaert, 2018). Furthermore, studies have shown how health systems and host societies more broadly may also influence migrants' health negatively through racism (Pattillo et al., 2023) and religious discrimination, in particular, islamophobia (Samari, Alcalá and Sharif, 2018), which is the case of Spain (Gil-Benumea, 2023).

Social networks and migrant health

In my thesis, I dedicate particular attention to immigrant women's social networks and how these may influence their health behaviours (i.e., screening) and access to healthcare services. It has been demonstrated that migration has a significant impact on immigrants' personal networks, for instance, reducing the number of family and friends as a result of the geographical distance, but at the same time increasing the opportunity to build new relationships with other migrants and non-migrants in the host country (Ryan, 2011).

This change in social interaction patterns may influence the availability of social support, including emotional, material or informational, which ultimately affects people's health and wellbeing (Thois, 2011). Additionally, the transmission of knowledge and information and the creation of social norms through social networks may also influence immigrants' behaviours. For instance, social ties may promote healthy or unhealthy behaviours, which in turn affect positive or negatively health outcomes (Uchino 2006, Umberson 2010).

Numerous studies suggest that homophily (the phenomenon that people principally form relationships with those who are similar to them) is a prominent characteristic of migrant social networks (Rostila, 2010). For example, Ryan et al. (2008) found that strong, co-ethnic ties (e.g. immigrant relatives) are crucial for basic support needs during the early immigration phases (e.g. help searching jobs and housing), but risk locking migrants into disadvantaged ‘ethnic niches’ over time. On the other hand, non-ethnic ties play a key role for subsequent socioeconomic mobility, but migrants may be more or less able to establish them depending on individual characteristics such as ethnicity, migration experience, length of stay in the host country and linguistic skills.

In terms of migrant health, Rostila (2010) found that migrants in networks with a high proportion of other migrants experienced poorer health than those who include a high proportion of natives in their networks. Similarly, other studies in Sweden and China (Åkerman et al., 2016; Li and Wu, 2010) associated ethnic homophily with inadequate access to and use of health information and services. By contrast, a study conducted in the US with migrant women from Guatemala (Menjívar, 2002) showed how women exchanged health knowledge with other peer migrants, such as a variety of treatments including prescription drugs and ‘traditional’ medicine.

1.2.2 Health-related terms

Health disparities

‘Health disparities’ is another key term used throughout my thesis that needs to be defined to avoid ambiguity, as it is often used interchangeably along with ‘health inequities’ and ‘health inequalities’. For the purpose of this thesis, I adopted the definition proposed by Healthy People 2020, which describes a ‘health disparity’ as:

“..... a particular type of health difference that is closely linked with economic, social, or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic - status, gender, age, or mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion”.

In my thesis, I use interchangeably the terms ‘health disparities’ and ‘health inequities’, rather than ‘health inequalities’, as the term ‘health inequities’ is related to ‘social justice in health’ (i.e., no one is denied the possibility to be healthy for belonging to a group that has historically been economically/socially disadvantaged), rather than the merely ‘differences in health’ linked to the term

‘health inequality’. As Braveman (2014) states, ‘health equity’ is the principle underlying a commitment to reduce—and, ultimately, eliminate—disparities in health and in its determinants, including social determinants. Pursuing ‘health equity’ means striving for the highest possible standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on social conditions. ‘Health equity’ and ‘health disparities’ are intertwined. As Whitehead and Dahlgren (2006) conclude, a reduction in health disparities (in absolute and relative terms) is evidence that we are moving toward greater ‘health equity’.

Health behaviours and self-care

Similar terms such as health behaviour, health(care)-seeking behaviour and help-seeking behaviour are often used interchangeably in the health promotion literature, however, they have different connotations, and their correct use is important in terms of targeting specific health prevention interventions.

The overall term health behaviour has been defined in different ways. For instance, Conner and Norman (2005) define it as any activity undertaken for the purpose of preventing or detecting disease or for improving health and wellbeing. Another definition proposed by Gochman (1997, p. 3) refers to as “*behaviour patterns, actions and habits that relate to health maintenance, to health restoration and to health improvement*” (Gochman, 1997, p. 3). A variety of behaviours fall within this definition including reducing or stopping smoking, moderating alcohol use, adopting a healthy diet, physical activity, safe sex behaviours, physician visits, medication adherence, screening and vaccination (Conner and Norman, 2017). Whereas smoking, alcohol consumption, diet, physical activity and sexual behaviours are self-directed health behaviours and often grouped under the category of ‘lifestyle’ behaviours, physician visits, screening and vaccination are related to medical service usage and are considered ‘preventive health behaviours’, which include any activity undertaken by an individual who believes him- or herself to be healthy, for the purpose of preventing or detecting illness in an asymptomatic state (Glanz and Stryker, 2008).

Self-care is a multidimensional concept that involves health behaviours (actions). It used to be applied to the management of chronic diseases (Martinez et al., 2021) until recently when the concept of self-care started to refer to actions taken not only by people with an existing health problem to self-manage their illness, but also by healthy people to prevent disease and maintain health. For the purpose of this thesis, I use as a primary reference the latest definition of self-care proposed by WHO (2013): “*the ability of individuals, families and communities to promote health, prevent disease, maintain health and to cope with illness and disability with or without the support of a healthcare provider*”, as it includes both ‘lifestyle’ behaviours and ‘preventive health behaviours’.

According to the above definitions, screening behaviour is a ‘preventive health behaviour’ that involves seeking healthcare services (e.g. Pap smear, HPV self-sampling) to detect early a disease (CC) or infection (HPV) in an asymptomatic state. Attending a screening programme differs, therefore, from seeking help for (cancer) symptoms: women may be asymptomatic when attending screening, whereas help-seeking requires awareness of potential symptoms of a diseases that then prompts the help-seeking process (Cornally and McCarthy, 2011). However, since a woman may be aware of a symptom and decide to wait for her next routine screening to have this examined, screening in this case would become part of the help-seeking process. Yet, they can be considered together as they are both practices to enable early detection and are both potential health care-avoiding actions (Grimley, Kato and Grunfeld, 2019).

The term help-seeking is often used interchangeably with health(care)-seeking (Cornally and McCarthy, 2011). Authors provide different definitions for both terms. Help-seeking behaviour has been defined as “*a response to health changes and part of the broader process of health-seeking behaviour*” (O’Mahony and Hegarty, 2009) and health-seeking behaviour has been defined as “*the action taken by an individual in response to a stimulus (such as the perception of a symptom) that the person decides is indicative of a condition needing evaluation by a health professional*” or “*any activity undertaken by individuals who perceived themselves to have a health problem or to be ill for purpose of finding an appropriate remedy*” (Oberoi et al., 2016; Gilliland et al., 1999; Ward, Mertens and Thomas, 1997). Other sources have defined health-seeking behaviours more broadly as “*personal actions to promote optimum wellness, recovery and rehabilitation*” (Nursing Outcomes Classification, 2010).

For the purpose of this thesis and to avoid confusion, I use the terms ‘screening behaviour’ and ‘preventive health behaviour’ or ‘health behaviour’ throughout the study.

1.3 Motivations and formulation of the study

This thesis is part of my own migration history from Spain to the UK more than a decade ago. According to the migration literature, I am an ‘economic migrant’, a person who leaves their country of origin in order to seek material improvement in their livelihood (EU Migration and Home Affairs, 2024), but I feel this definition simplifies the complex circumstances that may lead a person to leave their country. Regardless the reasons for migration, a range of factors, including country of origin, socioeconomic status, education, religion, having or not family in the host country - just to name a few - make each personal experience of migration different. However, there are also common barriers that many migrants face, especially during the first years of the migration process: the language

barrier and/or the culture shock, which is defined as the unexpected and often negative reaction of people to new environments (Furnham, 2019) and a psychosocial process that involves managing stress and coping with an unfamiliar environment, learning new culture-specific skills, or enhancing intercultural relations (Ward, Bochner and Furnham, 2001).

Looking back, I have personally experienced both (language barriers and culture shock) and I recognise that some of the most challenging situations occurred when interacting with the health system (e.g. NHS). Despite being an European immigrant and having universal access to public health care services in the UK, I have always found it difficult to establish a trusting patient-doctor relationship because of different factors: my limitations and insecurity to express in another language specific symptoms and health problems; the providers' health communication approach which I find 'colder' than in Spain; my initial unfamiliarity with the health system, and my constant mobility within and between cities in the UK. In the past ten years, I have had the opportunity to share these and other 'migration experiences' with other immigrants from Africa, Asia, East Europe, South America. My and their accounts inspired me to use my journalism skills and publish a number of articles reporting the barriers that Ethiopian immigrant women face to access healthcare in Saudi Arabia. This led me to also conduct research on internal migration of young Ethiopian girls in Tigray Region, Ethiopia. Back in Scotland, I also had the opportunity to work with researchers investigating health and psychosocial well-being of migrant populations, using social network and social support analysis methods. All these personal and professional experiences have contributed to my interest in migrant health and healthcare accessibility in particular, from a medical sociology and anthropology perspectives, with especial attention to the role of social networks on migrants' health and health behaviours.

Migrants' health and the role of social networks on their health and health behaviours were, therefore, the two central elements of my original PhD project, planned to be conducted in Tigray, Ethiopia. However, the conflict in this region and the COVID-19 pandemic significantly impacted the feasibility of the research, and I had to rethink the study and change the setting. My brainstorming brought together these two central elements: migrants' health and social network analysis (SNA) methods, and the prevention of HPV and cervical cancer, as I explain below.

My interest in and commitment to women's sexual and reproductive health and rights (SRHR) have led me in previous years to becoming involved in various research and advocacy projects addressing the impact of lack of access to safe abortion services, especially in LMICs (e.g. El Salvador, Peru, Panama, Cameroon). One of the many things I have learned from my interviews with women in these countries is the lack of empowerment of women to make informed health decisions, in part because of the cultural and social contexts in where they live, but in many cases also due to a lack of accurate

information. In previous research, I discovered that women had limited information and/or misconceptions about abortion. Similarly, I found that information about sexually transmitted infections (STIs) and how to protect oneself from them was inadequate in some disadvantaged communities. For instance, although HPV infection is one of the most common STIs worldwide, I was struck by the lack of awareness about this ‘invisible’ sexual health infection and its causal relationship with CC in general. I observed this lack of awareness, not only in the research settings, but also among some of my friends (immigrants and non-immigrants) in Spain and the UK.

This led me to wonder to what extent immigrant women, especially from non-Western countries, in Europe, were aware of this cancer and to what extent they vaccinated their children against HPV and participated in CC screening programmes. After some research, I confirmed the low participation rates in CC screening programmes amongst immigrant women and their distrust in certain vaccines, such as HPV. In my literature search, I also found research papers applying SNA methods to explore the role of social interactions on women’s screening behaviours. With these ideas, I contacted by email a researcher of the Catalan Institute of Oncology (ICO) and I proposed a study to investigate HPV and CC prevention attitudes and behaviours (e.g. HPV vaccine) amongst immigrant women in Barcelona. After a few phone calls and a meeting in person in Barcelona with two researchers, ICO accepted my proposal and we agreed to focus the study on CC screening amongst immigrants from Pakistan and Morocco, using SNA methods and putting special attention to HPV self-sampling acceptability in these two groups of women. Then, they provided me with the necessary contacts to conduct the study, the results of which are presented in this thesis.

This thesis is, therefore, the result of my personal background as an immigrant woman in the UK, my work experience and connection with SNA researchers, and of my commitment to improving women’s access to healthcare and to empower them to make informed decisions, especially about their SRH. The thesis reflects my efforts to better understand barriers and facilitators to access and use healthcare services, such as CC prevention programmes, amongst immigrants, and ultimately propose solutions to address persistent health inequities amongst these populations.

1.4 Funding and collaborating partners

This PhD study was funded by the Economic and Social Research Council (ESRC) in the United Kingdom under the UBEL Doctoral Training Partnership scholarship scheme [grant number ES-

P000592/1]. The London School of Hygiene and Tropical Medicine also contributed with additional funding to cover fieldwork expenses in Barcelona, Spain.

Since 2021, opportunistic screening pilot projects have been taking place in different municipalities of Barcelona province to inform the broader implementation of the newly organised population-based CC screening programme across Catalonia (Catalan Institute of Oncology, 2024). My research is embedded in these pilot studies and is specifically focused on addressing screening disparities among immigrant populations. I conducted my research in collaboration with the Catalan Institute of Oncology (ICO) and the Public and Community Health team from the Drassanes International Health Unit - Vall d'Hebron Hospital.

ICO, through the Cancer Research Epidemiology Programme and the Oncology Directive Plan, is leading the implementation of the Catalan organised population-based screening programme, which includes the introduction of HPV self-sampling as a primary sample collection method for CC screening. Within this broader implementation programme, I led this specific study targeting immigrant women from Morocco and Pakistan, which is a stand-alone piece of research and part of my PhD programme at the Faculty of Public Health and Policy, at London School of Hygiene and Tropical Medicine (LSHTM). The Public and Community Health team from the Drassanes International Health Unit - Vall d'Hebron Hospital, which has extensive experience in working with immigrants from different backgrounds in Barcelona, assisted me in the recruitment of research assistants (RAs) and participants, and in the data collection process, including moderating focus groups, conducting some interviews, helping to administer the survey questionnaires and transcribing/translating the audio recordings.

1.5 Aim and Objectives

The ultimate goal of this study is to help inform future adaptations of the CC screening programme in Catalonia, Spain, and/or the design of tailored interventions to increase CC screening participation among Moroccan and Pakistani immigrant women. At the first stage, the overall aim of this study was to explore and understand the barriers and facilitators to CC screening among these two populations and examine the acceptability of HPV self-sampling to them in the context of the newly organised population-based CC screening programme in this Spanish region.

To achieve this, the research objectives were:

- 1) To explore individual and health system determinants of CC screening behaviours among Moroccan and Pakistani immigrant women in Catalonia, Spain.
- 2) To understand how Moroccan and Pakistani immigrant women's social interactions affect their CC screening behaviours.
- 3) To identify suitable strategies to increase CC screening uptake among these two groups of women and to provide specific recommendations for the implementation of HPV self-sampling as a primary sample collection method for CC screening among these communities in Catalonia, Spain.

1.6 Research questions

The research questions for the exploration of individual factors influencing Moroccan and Pakistani women's participation in CC screening programmes in Catalonia, Spain, were as follows:

Research question 1: What are the knowledge and perceptions of Moroccan and Pakistani immigrant women about CC and HPV, and screening programmes in Catalonia, Spain?

The research question and sub-questions related to the influence of social interactions on women's CC screening behaviours were as follows:

Research question 2: How do social networks influence Moroccan and Pakistani immigrant women's preventive health behaviours, and specifically, their participation in CC screening programmes?

Research sub-questions:

- What do Moroccan and Pakistani immigrant women's personal networks look like?
- To whom would they turn for information and advice about sexual and reproductive health (SRH) matters?

The research question for the exploration of health system barriers was formulated as follows:

Research question 3: What are the main challenges to accessibility and provision of SRH services, especially CC screening, to immigrant women in Catalonia, Spain?

Finally, the fourth research question was formulated as follows:

Research question 4: Which strategies are most suitable to increasing Moroccan and Pakistani immigrant women’s CC screening uptake? Specifically, what are the opportunities and challenges of HPV self-sampling as a primary sample collection method for CC screening?

Research sub-questions:

- What are the screening preferences for Moroccan and Pakistani immigrant women?
- Would they accept HPV self-collection as a sampling method for CC screening?

Table 2 provides a summary of each objective with its corresponding research questions and chapters.

Table 2 Study objectives and research questions.

Objectives	Research questions and sub-questions	Chapters
1. To explore individual and health system determinants of CC screening behaviours among Moroccan and Pakistani immigrant women in Catalonia, Spain.	RQ1. What are the knowledge and perceptions of Moroccan and Pakistani immigrant women about CC and HPV, and screening programmes in Catalonia, Spain?	#5, 7, 8
	RQ3. What are the main challenges to the accessibility and provision of SRH services, especially CC screening, to immigrant women in Catalonia, Spain?	
2. To understand how Moroccan and Pakistani immigrant women’s social interactions affect their CC screening behaviours.	RQ2. How do social networks influence Moroccan and Pakistani immigrant women’s preventive health behaviours, and specifically, their participation in CC screening programmes?	#6
	<ul style="list-style-type: none"> - What do Moroccan and Pakistani immigrant women’s personal networks look like? - Whom they would turn to for information and advice about SRH matters? 	
3. To identify suitable strategies to increase CC	RQ4. Which strategies are most suitable to increasing Moroccan and Pakistani immigrant	#5, 6, 7, 8

screening uptake among these two groups of women and to provide specific recommendations for the implementation of HPV self-sampling as a primary CC screening strategy among these communities in Catalonia, Spain.

women's CC screening uptake? Specifically, what are the opportunities and challenges of HPV self-sampling as a primary sample collection method for CC screening?

- What are the screening preferences for Moroccan and Pakistani immigrant women?
- Would they accept HPV self-collection as a sampling method for CC screening?

1.7 Structure of the thesis

This 'research paper style' thesis comprises four interrelated research papers, which contribute to the overall study by exploring barriers and facilitators to CC screening from different levels of analysis (e.g. individual, interpersonal, health system), applying a range of theories and research methods and including the perspectives of Moroccan and Pakistani immigrant women and healthcare providers.

In Chapter 1, I explain the important role that organised population-based screening programmes have had and still have in reducing CC incidence and deaths, even when primary prevention strategies (i.e. HPV vaccination) are in place. I provide evidence on the effect of persistent disparities in screening participation on disadvantaged groups, such as immigrant populations across Europe, including Spain. Based on this evidence, I argue the need to address these screening disparities and I introduce the CC screening context in Spain and Catalonia, as well as the case study of Moroccan and Pakistani immigrant women. In Chapter 2, I provide a comprehensive review of the literature focused on the epidemiology of the disease with special attention to immigrant populations, determinants of screening participation, as well as current strategies to increase uptake, such as HPV self-sampling. In Chapter 3, I present the theoretical frameworks and models applied throughout the study and how they were used, and in Chapter 4, I explain the rationale for using a qualitative-driven mixed-method research design and each specific method, as well as a description of the data collection process and the design of the research instruments. In Chapters 5 through 8, I present the findings of four research analyses. Each chapter begins with a brief introduction to explain the objectives of the research paper and the links to the other research papers. I describe below each of the research papers:

In Chapter 5, I begin by introducing the concepts of self-care and prevention and how these have evolved over time, and by describing the domains of one of the frameworks often used to assess individuals' engagement with self-care and prevention practices. I then present the results of an in-depth qualitative exploration of Moroccan and Pakistani immigrant women's self-care and prevention attitudes and practices, and I end by discussing the extent to which

‘Western’ concepts of self-care and prevention (e.g. general check-ups, CC screening) are meaningful to individuals with different cultural backgrounds.

In Chapter 6, I first present evidence on the importance of integrating social influence approaches into health education programmes to improve CC screening participation. I then briefly explain social norms and social networks theories and how these have been applied in some behavioural studies addressing CC screening in order to support the rationale of the study. After a detailed explanation of the methods (egocentric social network analysis and qualitative interviews), I discuss the potential social influences on Moroccan and Pakistani women’s CC screening behaviours.

In Chapter 7, I begin by reporting my findings on how communication barriers due to language limitations and cultural differences may undermine immigrant women’s right to benefit from preventive programmes, including CC screening, and make informed decisions. I then introduce the concept of cultural competence in the provision of healthcare and explain its benefits from the patient and health system perspective. Afterwards, I describe the communication barriers between immigrant patients and healthcare providers, and provide recommendations for a more culturally competent health system in Catalonia, Spain.

In Chapter 8, I first discuss the opportunities and challenges that HPV self-sampling has posed in different populations and settings. I then explain the qualitative and quantitative methods used to explore knowledge and risk perception towards HPV and CC, and assess the acceptability of HPV self-sampling among Moroccan and Pakistani immigrant women. Finally, I provide recommendations for a successful implementation of HPV self-sampling among these two groups of women in Catalonia, Spain.

In Chapter 9, I provide a summary of the findings of these four analyses to guide the reader and discuss the implications of these. I then provide long, medium and short-term recommendations for policy makers and practitioners to ensure equitable and effective population-based screening programmes in Catalonia, Spain and specific strategies to increase awareness about CC and screening uptake among these two groups of women.

1.8 Relevance of the study

This study makes a number of relevant contributions to the cancer prevention literature. First, it identifies cultural and ethnic-specific barriers and facilitators to CC screening among Moroccan and Pakistani immigrant women in the context of the Catalan health system in Spain. To date, of the very

few identified studies addressing CC screening among immigrants in Spain, all were cross-sectional surveys confirming low participation rates, but none provided qualitative insights into the determinants of cervical screening uptake. This is the first qualitative-driven mixed-method study that provides an in-depth multi-level analysis to understanding individual, interpersonal and health system factors influencing Moroccan and Pakistani women's screening behaviours in Spain. This mixed-methods approach also allows for the comparison of two communities that share certain religious and other cultural values, but differ in traditions and their migration history to Spain (Moroccan immigrants have been living in Spain longer than Pakistani immigrants), which impact differently on their health behaviours (e.g. screening). For example, the qualitative findings of the study show how immigrants adopt certain cultural values and practices from the host country, in this case, Catalonia/Spain, which may also affect women's screening behaviours.

Second, this is the first study assessing HPV self-sampling acceptability among immigrants in Spain. To date, a few studies have addressed acceptability of HPV self-sampling among Spanish women, but none has explored potential challenges for the implementation of HPV self-sampling among immigrants from non-Western countries. Therefore, this study is also relevant because results will begin to build an evidence base for more equitable CC screening programmes and the implementation of HPV self-sampling among immigrant populations in Catalonia and the rest of the Spanish regions, by providing pre-implementation data (i.e. acceptability) regarding these two specific ethnic groups.

Third, this study contributes to the limited literature on social network analysis (SNA) methods applied to cancer prevention research. Although there are a few egocentric studies measuring the effect of social norms and social networks on CC screening behaviours, to the best of my knowledge, this is the first study combining an egocentric approach with network graphs and narratives to analyse immigrants' social networks and their potential role in CC screening behaviours. This analysis approach could be beneficial for the design of more effective behaviour change interventions, leveraging peer migrants to influence cultural values and practices and improve preventive health behaviours.

Overall, the knowledge generated from this study will help to inform other researchers, public health practitioners and policy makers interested in applying UHC principles into cancer prevention programmes and, particularly, in ensuring an equitable population-based screening programme in Catalonia, through the adaptation or design of tailored interventions for immigrant populations.

1.9 Contribution of the author

While ICO is leading the implementation of the broader organised population-based CC screening programme in Catalonia, the conceptualization, design, implementation, analysis and dissemination of this PhD project was entrusted to me. I led all the research stages of the study, under the supervision of my two supervisors Joanna Busza (LSHTM) and Guy Harling (University College London - UCL), as well as the member of my PhD Advisory Committee, Clare Gilham (LSHTM).

I spent nine months in Barcelona, where I led the start-up of the project, recruitment of RAs, facilitation of trainings, recruitment of participants, fieldwork activities and supervision and management of data, with the support of a researcher from ICO (Paula Peremiquel Trillas) and the coordinator of the Public and Community Health team of Drassanes – Vall d’Hebron Hospital (Hakima Ouabarab Essadek). I held meetings every two weeks with these two collaborators to discuss progress on the participant recruitment process, data collection issues, solving questions related to the interview topic guides and survey questionnaires, and to coordinate the logistics for the focus group discussions (FGDs) and semi-structured interviews (SSIs).

I participated actively in the data collection process conducting all the key informant interviews (KIIs) with the health providers and half of the interviews with women from Pakistan and Morocco. The other half were conducted by the RAs, Khadija Mellouki and Andleed Sharif, who played also an important role in the recruitment of participants, translations and transcriptions of the audio-recordings from the SSIs and FGDs. I supervised the work of the RAs and I held meetings with them after each interview in order to identify emerging topics and discuss any issue during the interviews. Two members of the Public and Community Health team of Drassanes – Vall d’Hebron Hospital (Hakima Ouabarab Essadek and Sumaira Malik Hameed) were responsible for moderating the FGDs in the participants’ languages and I attended all the sessions as an observant with the permission of the participants. Briefing meetings were also held after the FGDs. ICO and I were responsible for the collection of the HPV self-sampling acceptability survey questionnaires and data entry in RedCap, and I supervised and managed all the qualitative and quantitative data sets.

I also led the data analysis process. Two researchers from ICO were involved in the first stages (i.e. development of codebooks, coding) and provided some input during the interpretation of the findings, specifically, in relation to the quantitative data concerning HPV self-sampling acceptability. Finally, I led the peer review process of the four research papers, which were revised and approved by all co-authors.

1.10 Dissemination of findings

With funding from the ESRC – UBEL DTP scheme, I presented part of my findings at two international events: the 7th European Conference on Social Networks, in Ljubljana (Slovenia), on 5 September 2023, and EUROGIN 2024 – the International Multidisciplinary HPV Congress, in Stockholm (Sweden) on 14 March 2024. In both cases, my abstracts were accepted for oral presentations. My abstract has also been accepted for poster presentation in the 36th International Papillomavirus Conference (IPVC 2024) which will take place in Edinburgh (UK) in November 2024.

Apart from these events, I actively engaged in the organisation of an online seminar: “Research in Action: Bridging Gaps in Cervical Cancer Prevention”, held on the 17 November 2023, at LSHTM, in which I also participated as speaker presenting part of my findings. Additionally, I presented the findings of my last research paper (Chapter 8) in the annual Poster Day event at LSHTM on the 18 April 2024, and I presented my project in various informal meetings with other earlier career researchers in the UK and Spain.

I was the lead author of four peer-reviewed publications (listed below) and I was responsible of the conception of the papers, analysis and writing up, with significant contributions from Joanna Busza in her role as my primary supervisor, and invaluable support from Guy Harling, my secondary supervisor, especially to conduct the egocentric social network analysis and visualization of network graphs. Because of the collaborating partnership, the members of the study team in Barcelona are co-authors based on their involvement in study design, data collection, interpretation of findings, or critical revisions of the papers, as appropriate in accordance with the International Committee of Medical Journal Editors (ICJME) authorship guidelines. All publications are currently or will be made available through open access journal articles or using repositories that comply with copyright requirements.

Paper 1 (Chapter 5) was published in 2024 in BMC Public Health:

Lurgain, J.G., Ouaarab-Essadek, H., Mellouki, K., Malik-Hameed, S., Sharif, A., Brotons, M., Bruni, L. and Peremiquel-Trillas, P. (2024) ‘Exploring self-care and cervical cancer prevention attitudes and practices among Moroccan and Pakistani immigrant women in Catalonia, Spain: a comparative qualitative study’, *BMC Public Health*, 24, 388. <https://doi.org/10.1186/s12889-023-17445-2>.

Paper 2 (Chapter 6) was submitted to BMC Women’s Health in January 2024:

Lurgain, J.G., Peremiquel-Trillas, P., Ouaarab-Essadek, H., Mellouki, K., Sharif, A., and Harling, G. (2024) ‘Social influences on Moroccan and Pakistani immigrant women’s access and use of cervical cancer screening in Catalonia, Spain: a social network analysis’, *BMC Women’s health* (Being revised for resubmission).

Paper 3 (Chapter 7) was published in 2024 in International Journal for Equity in Health:

Lurgain, J.G., Ouaarab-Essadek, H., Mellouki, K., Malik-Hameed, S., Sharif, A., Rangel-Sarmiento, V., Bruni, L., and Peremiquel-Trillas, P. (2024) ‘Exploring cultural competence barriers in the primary care sexual and reproductive health centres in Catalonia, Spain: perspectives from immigrant women and healthcare providers’, *International Journal for Equity in Health*, 23, 206. <https://doi.org/10.1186/s12939-024-02290-5>

Paper 4 (Chapter 8) was submitted to BMC Health Services Research in July 2024:

Lurgain, J.G., Peremiquel-Trillas, P., Ouaarab-Essadek, H., Mellouki, K., Malik-Hameed, S., Sharif, A., Rangel-Sarmiento, V., Bruni, L., Harling, G. and Gilham, C. (2024) ‘Moroccan and Pakistani women’s knowledge and perceptions of cervical cancer screening and HPV self-sampling acceptability in Catalonia, Spain: a mixed-methods study’, *BMC Health Services Research* (Under peer review).

Chapter 2 Background

2.1. Natural history of cervical cancer

HPV is the most common sexually transmitted viral infection worldwide. In Western countries, it is estimated that 80% of all sexually active women and men will contract at least one genital HPV infection in their lifetime (Chesson et al., 2014). There are more than 200 types of HPV that can be transmitted sexually, and at least 12 can cause cancer of the cervix and other sites (vagina, vulva, penis, ano-genital and non-genital oro-pharyngeal sites) (Bzhalava, Eklund and Dillner, 2015; Shukla et al., 2009; Bouvard et al., 2009). HPV 16 and 18 are the two most common oncogenic types and cause approximately 70% of all CCs worldwide (WHO, 2024). The majority of the infections are asymptomatic and although most women infected with the virus become negative within two years, women with persistent hrHPV infections are at greatest risk of having (pre)cancerous lesions (Cervical Intraepithelial Neoplasia or CIN1, CIN2, CIN3), which may progress to CC after 5 to 20 years (Steenbergen et al., 2014; Castellsague 2008; Trottier and Franco, 2006; Bosch et al., 2002). Although HPV is a necessary cause of CC, not all lesions lead to malignancy. Some cofactors, such as multiparity, young age at marriage, other sexually transmitted infections (STIs) (HIV and Chlamydia trachomatis), smoking and long-term use of oral contraceptives, in combination with HPV, cause the malignant deformities characteristic of cancer cells (Momenimovahed and Salehiniya, 2017).

The earliest evidence of the sexual transmission of CC came with historical anecdotes regarding Roman Catholic nuns' low risk of CC (Griffiths, 1991), later supported by epidemiological studies showing that women with multiple sex partners or having spouses with multiple sexual contacts were at an increased risk of contracting this cancer (Ley et al., 1991; Moscicki et al., 2001). While researching cancer of the cervix, Harald zur Hausen, a German virologist, discovered HPV as a human carcinogen and causative factor for onset and progression of genital neoplasia (Gissmann, 2006), for which he received the Nobel Prize in Physiology or Medicine 2008.

The knowledge that persistent hrHPV infection is the main cause of CC has resulted in the development of new tools of primary prevention, such as prophylactic HPV vaccines that are given at an early adolescent age. However, the widespread implementation of the HPV vaccine has been limited by economic constraints, the varying healthcare priorities of different countries, as well as the availability of the vaccine and, in some cases, vaccine hesitancy among populations and governments (e.g. Japan) (Shiraz et al., 2020). In this situation, cervical screening continues to play a critical role in the prevention of CC and will need to adapt to the changing incidence of HPV-associated neoplasia (Shiraz et al., 2020). As mentioned previously, CC screening has traditionally been performed using

Pap tests, but the knowledge of the role of HPV in CC progression has also resulted in new tools of secondary prevention, such as screening with validated HPV assays that detect nucleic acids of the virus. If implemented widely and wisely, these preventative approaches have the potential to complete Papanicolaou's (Pap test's discoverer) goal of CC eradication (Tan and Tatsumura, 2015).

2.2. Cervical cancer incidence and mortality

The difference in CC incidence and mortality rates depends on several factors such as the human development index (HDI), sexual behaviours, fertility patterns, and the participation rates in screening programmes (Momenimovahed and Salehiniya, 2017; Momenimovahed et al., 2023). According to global estimates from the year 2020 (Singh et al., 2023), age-standardised CC incidence was highest in East, West and Central Africa (ranging from 31.6 to 40.1 cases per 100,000 women-years) and lowest in Western Asia (4.1). Incidence was relatively low in Oceania, northern America, and most countries of Europe, with the exception of some countries in Central and Eastern Europe (e.g. Romania (22.6) and Bulgaria (18.0)). Mortality rates followed a similar pattern to incidence, with the highest mortality rates observed in Eastern Africa (28.6 deaths per 100 000 women-years) and the lowest rates observed in Western Europe (2.0). Specifically, CC incidence ranged from 2.2 in Iraq to 84.6 in Eswatini, and mortality rates ranged from 1.0 in Switzerland to 55.7 in Eswatini.

Consistent with the above trends, Spain is among the countries with the lowest CC incidence and mortality rates in the EU (Arbyn et al., 2007) and worldwide (Sánchez-Beiza, 2004). The estimation of new CC cases for 2024 in Spain was 2.26, which represents 1.8% of all new female cancer cases, and the number of deaths reached 655 in 2022 (1.4% of all female cancer deaths) (SEOM, 2024). However, some studies pointed out that changes in sexual behaviour, international tourism and migration have modified the probability of exposure to HPV, which may have affected the epidemiology of CC in Spain (Cervantes-Amat et al., 2015). Particularly, the social changes experienced since the 1980s -in the form of more liberal sexual behaviour and increased contact with people from regions with higher prevalence of HPV infection have increased the risk of exposure to HPV among Spanish female in general, and among the younger generations in particular. As a result, Cervantes-Amat et al. (2015) reported the end of the decline in CC mortality in Spain - a trend more evident in Spain's Mediterranean and Southern regions, and in women both in the 45- to 65- and over 65- year age ranges -. and they called for a transition from opportunistic to organised population-based screening programmes.

2.3. Cervical cancer among immigrant women

As mentioned in the introduction of this thesis, since immigrant women's participation rates in CC screening programmes are low, the risk to late diagnosis and treatment may increase, resulting in increased risk of mortality. However, data on CC incidence and mortality among immigrant women are scarce, in part due to incomplete and insufficient quality data coverage on migrants' health within the European health systems (Bozorgmehr et al., 2023). The very few studies identified provide mixed, and sometimes conflicting, results.

For instance, a study conducted in Italy revealed that the CC incidence trend decreased in Italian women (annual percent change = -2.7%), but increased in immigrants (APC = 12.2%) (Bucchi et al., 2019), whereas another population-based study published by Visioli et al. (2015), also in Italy, showed high-grade cervical lesions to be more common in Italy-born women than in immigrant women. In Finland, another study concluded that Russian-born immigrant women had an increased ($+62\%$) incidence of CC compared to the general Finnish female population (Lamminmäki et al., 2022). However, a study focused on four Nordic countries, including Finland, found that the CC incidence and mortality were lower among non-Western immigrants compared to native population (Sarkeala et al., 2023). This multi-country study found that the rate ratio of CC decreased with duration of residence and increased with rising age at immigration, suggesting that recently arrived immigrant women, especially those who are older, may be at higher risk to develop CC. Therefore, more efforts should be made to reach these specific migrant populations and ensure equal screening programmes. Similarly, research in the US found that older immigrant women had significantly higher CC mortality rates compared with US-born women (Hallowell et al., 2019). The same patterns were observed in a population-based study conducted in Australia, where incidence rates of CC were lower for many immigrant groups compared to Australian-born residents, with women from Southern Asia (IRR = 0.39; CI=0.30-0.50) and North Africa (IRR = 0.42; CI=0.23-0.77) having the lowest rates. Rates of CC were higher in immigrant women from New Zealand, Philippines, and Polynesia (Yu et al., 2022), suggesting that different factors, such as socio-demographic characteristics -country of origin, education- and different preventive health behaviour patterns may influence CC incidence.

In Spain, CC incidence and mortality rates among immigrant women are unknown. To the best of my knowledge, only a few regional studies have addressed CC or hrHPV-related rates among immigrant populations. In Catalonia, a study showed that immigrant women had a higher prevalence of cytological abnormalities compared to the Spain-born population, 4.5% and 2.9%, respectively ($p < 0.001$) (Rodríguez-Sales et al., 2013), and in Castilla y Leon, the results of another comparative study revealed that the prevalence of morphological and microbiological changes in immigrant women was greater. Low-grade squamous intraepithelial lesions (L-SIL) were more common in

immigrant women than in Spanish women, being present in 0.6% of the samples from foreign women versus 0.4% of the samples from Spanish women, as were high-grade squamous intraepithelial lesions (H-SIL) and cancerous lesions, where there was a greater difference, with the percentage tripling, from 0.1% in Spanish women to 0.3% in foreign-born women, and doubling, from 0.1% to 0.2% in malignant lesions ($p < 0.001$) (García-Villanueva et al., 2019).

The high burden of HPV infection closely correlates with the high incidence of CC in immigrant women (Tornesello et al., 2014). Thus, CC studies have also focused on estimating the prevalence of HPV. For instance, a study in Italy showed that the overall prevalence ratio of HPV infection in foreign women living in Southern Italy regions was 51.1% (255 out of 499) among cytological specimens observed, which was much higher compared to the infection frequencies of 13.4%, observed among 3,817 Italy-born women attending organised CC screening (Tornesello et al., 2014). The data of this study was the result of a pooled analysis based on three independent studies (Chironna et al., 2013; Tornesello et al., 2011; Giovannelli, et al., 2009) designed to assess the distribution and the prevalence of HPV genotypes among foreign women residing in Apulia, Campania and Sicily. In Apulia, the mean age of enrolled foreign women was 24 ± 4 years (range 13-41) with an overall HPV prevalence of 39.1%; in Sicily, the mean age of the migrants enrolled was 31.2 years (range 22-55) with a HPV prevalence of 42% and, in Campania, the participants' median age was 37.6 ± 10.8 years (range 20-69) with a prevalence of 57.9 HPV infection. Age-stratified HPV prevalence in the three regions showed a higher infection rate at younger ages with peaks of 53.1% among women ≤ 20 years old in Apulia and 70 and 68.3% in women aged 21-24 and 25-29, respectively, in Campania region, and 72.5% among women aged 22-27 in Sicily. It is important to note that these are not screening age populations, whereas the comparison group was composed of older Italian-born women attending organised CC screening.

Similarly, Garcia-Villanueva et al. (2019) revealed that the prevalence of HPV in immigrant women living in Spain (Castilla y Leon region) was 23.5%, significantly higher than in the Spain-born women ($p < 0.001$), and a study conducted in another Spanish region (Alicante) showed that the prevalence of hr-HPV was more than three times higher in Latin Americans than in Spaniards. Compared to Spain-born women (prevalence 8.2%) hr-HPV prevalence in Colombians was 27.5%, 23.1% in Ecuadoreans and 22.7% in women from other Latin American countries (Gonzalez et al., 2006). Data on CC incidence and mortality among Moroccan and Pakistani immigrant women living in Spain are unknown. However, some studies point to a resemblance or correlation between rates in immigrant populations and their countries of origins (Gonzalez et al., 2006).

2.4. Cervical cancer screening in Morocco and Pakistan

In Morocco, CC ranks as the second most common female cancer after breast cancer (Lalla Salma Foundation, 2012). According to the latest statistics published by the International Agency for Research on Cancer (IARC/ICO, 2023), the age-standardized incidence rate was equal to 10.4 new cases per 100,000 women per year and the age-standardized mortality rate was 5.8 per 100,000 women per year (Sung et al., 2021), which are, as in other North African countries, low compared to the rest of the African continent (ranging from 31.6 to 40.1 cases per 100,000). However, two studies conducted prior to and after the implementation of the Moroccan national CC screening programme in 2010, highlighted the alarming finding that many of the new CC cases are often diagnosed at very late stages. Berraho et al. (2012) found that 2/3 of reported cases were diagnosed and managed at a very advanced stage, and that the frequency of long total delay rate was higher among women from rural areas and illiterate. In their systematic review, Arechkik et al. (2022) also reported that 71.9% of Moroccan women who participated in seven studies (pooled percentage) were often diagnosed at advanced stages - comparable to other countries such as Kenya, Tanzania and Nigeria - and concluded that this finding is likely due to the low participation of women in the early detection programme for CC: 76.3% of women had never been tested. Consistent with this finding, the IARC evaluation of the Moroccan CC programme, showed that the coverage rate did not exceed 7.7% in 2016 (Selmouni et al., 2019), significantly lower than the coverage rate in European countries and in Spain (83%) (WHO, 2021, page 164).

Pakistan lacks an organised and comprehensive CC screening programme at the primary care level (Chughtai et al., 2023). Although some hospitals and clinics offer screening services, such as Pap smear tests, screening is not available in most parts of the country. The country's healthcare infrastructure is insufficient, and resources are limited, which makes it challenging to establish adequate screening programmes across the country (Amahd et al., 2023, Ali et al., 2010) to calculate the exact rate of incidence and prevalence of CC, as well as mortality rates (Batool, Sajjad and Malik et al., 2017).

Based on the available data, international agencies (IARC) estimate that CC ranks as the third most frequent cancer among women in Pakistan and the second most frequent cancer after breast cancer among women between 15 and 44 years of age (Singh et al., 2023). Every year, around 5,008 women are diagnosed with CC and 3,197 die from the disease in Pakistan. The age-standardized incidence rate was 6 new cases per 100,000 women per year and the age-standardized mortality rate was 4 per 100,000 women per year, respectively (IARC/ICO, 2023). Although there is limited data, women diagnosed with CC were reported with advanced stages of malignancy in Pakistan, as in Morocco. For instance, Aziz and Yousaf (2013) found that 75% cases were identified with stage II and III, and another study

conducted in Lahore (Badar, Anwar and Meerza, 2007) found that 67% cases presented with advanced stage II to IV. Late diagnosis is often associated with low participation in CC screening. In Pakistan, the uptake of Pap smears is very limited, estimated by one study to be as low as 2% (Sultana, Hafeez and Shafiq, 2019). Similarly, another study reported that only 2.6% of Pakistani women have a screening test once in their life (Gele et al., 2017).

2.5 Barriers to cervical cancer screening among immigrant women

A screening programme can only be effective if the target population is willing to engage with it. The reasons for participation in CC screening are multiple and complex and vary from one population to another. Systematic reviews addressing barriers to CC screening among immigrant women identified numerous individual, socio-cultural and health system related barriers, including socio-demographic characteristics (i.e. age, education, income level), lack of knowledge about the disease and screening tests, lack of effective communication, not being registered in the country's healthcare system, lack of free time, family obligations, sexual morality, sex of the healthcare provider and emotional responses to the test (i.e. embarrassment, fear, discomfort) (Marques et al., 2020; Ferdous et al., 2018). In the particular case of immigrant Muslim women, Afsah and Kaneko (2023) also emphasized barriers related to religious values, beliefs, and fatalism.

Acknowledging the similarities and differences between Moroccan and Pakistani immigrant women, low participation rates in CC screening have been associated in both cases with lack of awareness about CC and screening programmes, language limitations, lack of symptoms, not having a female physician, cultural and religious beliefs and subjective norms (Hamdiui et al., 2022a; Alam, Dean, Janda, 2022; Alam et al., 2022; Hilverda, Fissers and van den Broek; 2021, Badre-Esfahani et al., 2021; Gele et al 2017; Szarewski et al., 2009). These barriers are presented below, and they are organised using the three main levels of the socio-ecological model (SEM) that guided my study (see a brief description of this model in Chapter 3 and the conceptual framework derived from my study findings in Chapter 9).

2.5.1 Individual barriers

Studies have shown that Moroccan and Pakistani women have relatively low levels of awareness about CC, screening guidelines and cancer risk factors in their countries of origin, as well as their destination countries. Overall, unawareness about the existence of the HPV virus and the connection between HPV infection and CC was reported. For instance, in a study conducted in Morocco, more than 90% of the respondents admitted that they did not know what caused CC and some even after having CC for several years still did not know about the HPV virus (Ouasmani et al., 2016). Similarly,

in the Netherlands, Moroccan immigrant women who participated in a focus group study also reported not having knowledge about the cause of CC, nor that HPV was sexually transmittable (Hamdiui et al., 2022a). Regarding Pakistani immigrant women, in two studies conducted in Denmark and Norway, participants showed poor knowledge regarding HPV virus and its transmission pathways and link to CC: many were convinced that CC was an inherited disease, some believed that the causes of cancer were unknown and that it developed without previous signs/symptoms (Badre-Esfahani et al., 2021; Gele et al., 2017). Lack of knowledge among older Pakistani women was also reported in a study conducted in the UK (Marlow et al., 2019). This lack of knowledge about the connection between HPV and CC was also observed in studies conducted in Pakistan, even among educated women (Sultana et al., 2019).

Lack of information about symptomatology of CC and unfamiliarity with screening programmes have also been commonly reported. More than 80% of participants in a hospital-based study in Morocco did not know the symptoms of CC (Belglaiia et al., 2018) and only 5% of participants in a study conducted in Lahore, Pakistan, knew that CC screening was available (Iman et al., 2008). In Iman et al.'s (2008) study, only 2.6% of the sample had ever received a Pap test and the most common reason cited was lack of information. In studies conducted in HICs, such as in Norway and the US, knowledge about the screening programmes and screening uptake seemed to be associated with the length of stay in the country (Møen et al., 2017; Luque et al., 2011). Similarly, another study conducted in Australia among South Asian immigrants, including Pakistani women, found that participants living in the country for 5–10 years (OR: 4.61; 95% CI: 1.35–17.28) or more than 10 years (OR: 8.58; 95% CI: 2.32–37.27) compared with those living for less than 5 years were more likely to have been screened (Alam, Dean and Janda, 2022).

Some studies have highlighted that the concept of health prevention differs from one culture to another (Kwok and Sullivan, 2007). In a qualitative study conducted in Australia with South Asian women, including Pakistanis, participants were unfamiliar with concepts of prevention and explained that they used healthcare services only when unwell (Alam et al., 2022). Similarly, in a quantitative study conducted in the UK with diverse ethnic minority groups, including Pakistanis, the belief that screening was unnecessary in the absence of symptoms was also reported (Marlow, Wardle and Waller, 2015). In other studies, Pakistani women reported that they believed only those who suspect themselves of having the disease should seek the screening, suggesting lack of understanding of early detection as a preventive measure (Badre-Esfahani et al., 2021; Gele et al., 2017).

Of the two studies identified addressing barriers to CC screening among Moroccan immigrant women, both conducted in the Netherlands, neither mentioned the absence of symptoms as a barrier to CC screening. In these studies, women showed a positive opinion regarding the need to get screened:

“prevention is better than cure” (Hamdiui et al., 2022a; Hilverda, Fissers and Van den Broek, 2021). However, in a study conducted in Morocco, 40% of participants considered the absence of symptoms the main reason for not getting screened (Bendahhou et al., 2023), followed by thinking they were not eligible (23%) and a lack of awareness of the programme (23%). Similarly, in another study conducted in Morocco, 47% of women mentioned the lack of symptoms as the main reason for not seeking Pap smear (Belglaiaa et al., 2018).

The fact that most participants were second-generation immigrants (see definition in the Introduction, section 1.2) in one of the above studies conducted in the Netherlands and potential social desirability bias might have overshadowed this important barrier related to the absence of symptoms among Moroccan immigrant women. It is important to note that the lack of symptoms may not be a reason for not participating in CC screening among younger and second-generation immigrants or those immigrants living in the host country longer. For instance, in a study conducted with Somali women, younger participants acknowledged that in Somalia it was customary to go to the doctor only when unwell, however, they explained that they adopted the practice of going for routine preventive care for themselves and their children in the host country (Raymon et al., 2014).

2.5.2 Interpersonal/community barriers

Cultural values and religious beliefs have been identified as important determinants of CC screening behaviours among immigrant Muslim women (Afsah et al., 2023; Ferdous et al., 2018). A study conducted in Canada concluded that being born in a Muslim-majority country was significantly associated with lower likelihood of being up-to-date on Pap testing (ARR=0.93; 95% CI: 0.92-0.93) (Lofters et al., 2017).

Virginity before marriage is an important value in Muslim societies such as Morocco and Pakistan. The fact that CC screening requires a vaginal examination was identified as an important obstacle, not only because it was perceived as exposing and embarrassing, but also because the test is seen to potentially affect virginity. Thus, it was believed that testing can only be performed when women are married (Hilverda, Fissers and Van den Broek, 2021; Badre-Esfahani et al., 2021; Tatari et al., 2020). Having fewer sexual partners compared to non-Muslims led Moroccan participants to have very low risk perception of developing CC and, consequently not participating in CC screening (Hamdiui et al., 2022a). Similarly, in a quantitative study conducted with Pakistani immigrant women, low risk perception was also the most reported common barrier to CC screening (75.7%) (Alam, Dean and Janda, 2022).

The literature also includes studies that show how religious beliefs can be both a barrier to and facilitator of CC screening among immigrant Muslim women from different countries, including Turkish (Duran et al., 2011), Somalian (Addawe, Mburu and Madar, 2018; Pratt et al. 2017; Tatari et al., 2020), Moroccan (Hamdiui et al., 2022a) and Pakistani women (Alam et al., 2022). In some studies, it has been reported that some believe the possibility of developing cancer is God's will and that letting the disease run its course is the right thing according to God's destiny, which would undermine participation in CC screening. In contrast, other studies have reported the belief that individuals have the responsibility of using the treatment and care that God provides to maintain the health that God has given them or to cure diseases according to God's will, which would serve as a facilitator to encourage women to get screened (Afsah and Kaneko, 2023). In the qualitative study conducted by Hiamdiui et al. (2022a) in the Netherlands, Moroccan participants considered religion to be a facilitator of CC screening. They expressed their belief that health plays an important role in Islam and that according to the Quran, it is important to take care of one's body using all available medical options. In the case of Pakistani women, in the study conducted by Alam et al. (2022) in Australia, faith was also viewed as a facilitator to CC screening. Participants saw religion as encouraging people to ensure healthcare, suggesting an understanding of faith and health prevention as an integrated experience.

The influence of gender norms on immigrant women's health behaviours was another salient determinant to CC screening among immigrant women identified in the literature (Afsah and Kaneko, 2023; Marques et al., 2020, Ferdous et al., 2018; Anderson de Cuevas et al., 2018). A number of studies reported women's tendency to place the health and well-being of their families over their own health and well-being, leading them to prioritise family responsibilities over CC screening (Islam et al., 2017; Hulme et al., 2016; Oelke and Vollman, 2007). For instance, in a cross-sectional survey, almost 40% of South Asian women reported lack of time and having other priorities, such as work, childcare and home duties, as one of the main reasons for not attending CC screening (Alam, Dean and Janda, 2022). Healthcare providers also observed this tendency of women to not prioritise CC screening, or even if they found it relevant, they did not have time to attend due to other priorities, including children (Olsson et al., 2014; Møen et al., 2018). In contrast, some studies showed family responsibility to be a facilitator, as some women felt a strong responsibility to remain in good health to protect family members, which could thus facilitate screening attendance (Kwok and Sullivan, 2007). In the case of Moroccan and Pakistani immigrant women, the identified studies did not highlight this tendency to place the health of families and home-related responsibilities (i.e. childcare) over their own health as a significant barrier to CC screening.

A growing body of the literature has placed more attention on the influence of social norms and social support on women's CC screening behaviours. For instance, Griva, Anagnostopoulos and Madoglou

(2009) concluded that women had the intention to participate in screening programmes when people who were important to them thought that they should do so. In the study published by Hamdiui et al. (2022a), some Moroccan immigrant women were afraid of what others would think if they participate in the screening programme, for instance, that it might be assumed they had multiple partners, thus deterring them from screening. Furthermore, in a study conducted in the US, women who reported having friends and family members to talk to about cancer screening were approximately three times more likely to complete any screening test than those who did not ($P = 0.127$) (Sewali et al., 2015).

The role of husbands and other relatives (i.e. parents, in-laws) in women's health decisions was emphasized in various qualitative studies with South Asians in Australia (Alam et al., 2022) and Moroccans in the Netherlands (Hamdiui et al., 2022a). In the study conducted in Australia, participants explained that in their cultures, women felt reluctant in taking health decisions on their own and usually involved husbands, showing their potential influence on screening uptake. In another study with Sikh women, female patients reported being unable to access cancer screening services unless approved to do so by the head of the family or by their partner (Oelke and Wollman, 2007). This influencing role of the male partners has been reflected in other studies with immigrant Muslim populations. In a study conducted in the US, immigrant participants expressed that some Muslim men were against screening, particularly if it was performed by male providers, and they considered it important to address men's lack of knowledge about screening (Zorogastua et al., 2017). In Sweden, a study led by doulas - non-medical persons who provide support in pregnancy, birth and in the postnatal period (Doula UK, 2024) - reported similar findings in relation to men preventing their wives from taking the test and also highlighted the relevance of informing men about screening services (Olsson et al., 2014).

The literature also emphasized the influential roles of healthcare providers and faith leaders in encouraging women to get screened for CC. Many immigrant women considered physicians to be trusted and authoritative figures and if the physician did not recommend a test, the patient believed it to be unnecessary (Vahabi and Lofters, 2016). Related to this, studies indicated a lack of physician recommendation for the screening test (Vahabi and Lofters, 2016; Hislop et al., 2004). Similarly, Muslim immigrant participants in the US expressed how support from the Imam was essential and that he should be engaged in information sessions about screening (Zorogastua et al., 2017).

2.5.3 Health system barriers

Language limitations are one of the most commonly cited barriers in the CC screening literature focusing on immigrant populations (Marques et al., 2020; Ferdous et al., 2018). Studies reported that information about preventive health services, including CC screening, was often provided only in the

host country's official languages, which prevented immigrant women from accessing information about these programmes (Himdiui et al., 2022a; Hilverda, Fissers and Van den Broek, 2021; Akhagba, 2017; Abdullahi et al., 2009). For instance, in the Netherlands, Moroccan women, especially older generations, reported not being able to understand the screening invitation letters and information brochures, as they were written only in Dutch (Hamdiui et al., 2022a; Hilverda, Fissers and Van den Broek, 2021), and in Norway, Pakistani immigrant women seemed to be unaware of their right to request a professional translator, leading them to use informal translation services from their husbands and relatives (Gele et al., 2017). In the cross-sectional survey conducted by Alam, Dean and Janda (2022) in Australia, 14.4% of the South Asian participants reported not having information about the Pap test in their native languages was a barrier to CC screening.

Regardless of women's country of origin and ethnicity, preference for a female provider when undertaking a Pap test has been reported in numerous studies. However, in the case of immigrant Muslim women, this preference holds even more importance due to the religio-cultural environments where they are coming from, in which gender segregation and modesty are important societal norms (Aubrey et al., 2017).

Lack of availability of female healthcare providers to perform the screening test when the patient requires it, is one of the barriers to CC screening most reported by immigrant women (Marques et al., 2023; Christie-de Jong et al., 2022; Azhar et al., 2022; Møen et al. 2018, 2017; Grandahl et al., 2015; Steven et al 2004; Jackson et al., 2002). In a study conducted with Chinese immigrants in the US, participants explained that they felt more comfortable discussing a Pap test and having an examination with a female physician (Jackson et al., 2002). Feelings of shame, awkwardness and shyness were the most common reasons for a same sex provider preference among Pakistani and Somali immigrants (Gele et al., 2017), but some studies also reported cultural and religious values as reasons for a same sex provider preference. For instance, for Somali women, having a male doctor performing the exam was not acceptable within their religion (Addawe, Mburu and Madar, 2018; Abdullahi et al., 2009). In the study conducted with Pakistani immigrant women in Norway, participants also expressed discomfort with male doctors, especially when involving genital examination and women reported that requests for a female doctor were not always met (Gele et al., 2017). Similarly, Moroccan participants mentioned that having a male primary care doctor was another reason for not getting screened and some of them reported not knowing about the possibility of requesting a female doctor or an assistant for the procedure (Hamdiui et al., 2022a).

In their scoping review, Marques et al. (2020) also highlight lack of access to healthcare services as another important health system barrier to CC screening among migrants, mainly by not being registered in the host country's healthcare system. Long waiting times, both to take the test and to

receive the results, also led women to postpone CC screening (Jackowska et al., 2012; Azerkan et al., 2015; Akhagba, 2017) (3.) . Finally, negative attitudes from healthcare professionals seemed to prevent women from attending CC screening, either by unprofessional treatment (Jackowska et al., 2012; Azerkan et al., 2015, Addawe, Brux Mburu and Madar, 2018) or failing to establish a good patient-healthcare provider relationship (Gele et al, 2017). Some women reported feeling discriminated against because of their migrant status or language skills (Jackowska et al., 2012), or their beliefs and culture were disrespected (Addawe, Brux Mburu and Madar, 2018). This could be exacerbated by a lack of skills to work with migrant women (Møen et al., 2018).

2.6 HPV self-sampling: a promising strategy to increase cervical screening uptake

In the last decades, a wide range of strategies have been used to overcome the above multidimensional barriers and to encourage women to undergo CC screening, including invitations, educational programmes, message framing (e.g. focusing attention of the message on specific characteristic of the target group: age, religion), health providers' counselling (Everett et al., 2011) and, more recently, the use of new technologies, such as game-based mobile apps (Wanberg et al., 2023; Orumaa et al., 2022), and new sample collection methods, such as HPV self-sampling (Serrano et al., 2022; Camara et al., 2021; Yeh et al., 2019; Verdoot et al., 2015).

Self-collection of samples (interchangeably termed self-sampling) occurs when individuals take a specimen themselves, either at the clinic or elsewhere, and send it to a laboratory for testing (Harding et al., 2017). Vaginal self-sampling was developed to address low STI testing rates among women, but its use for HPV testing is more recent. Studies have shown that using polymerase chain reaction (PCR) technology, self-collected samples are comparable in terms of sensitivity and specificity to clinician-collected samples (Petignat et al., 2007; Ogilvie et al., 2005; Szarewski et al., 2007). The rationale for using HPV self-sampling is mainly to improve screening participation rates as it is considered that the privacy afforded by self-sampling may encourage more women to get tested compared with Pap smears (Yeh et al., 2019), and the cost effectiveness of HPV self-sampling programmes (Malone et al. 2020).

HPV self-sampling was included in the WHO self-care intervention guidelines for health and wellbeing (WHO, 2022) after the COVID 19 pandemic, which accelerated the use of this self-collection method for CC screening (Rodriguez et al., 2023). The global use of self-sampling is likely to increase in the following years. Currently, among the 48 countries with HPV-based programmes, 17 (35%) reported having introduced self-sampling in their national programmes or guidelines, 9 as the primary collection method (e.g. Netherlands) and 8 to reach under-screened women (e.g. Australia, Sweden, Denmark, Finland, France) (Serrano et al., 2022).

As suggested above, HPV self-sampling interventions have demonstrated effectiveness in increasing CC screening. A meta-analysis - including randomized controlled trials (RCTs) conducted mainly in HICs - found greater screening uptake among HPV self-sampling participants compared with the control groups (e.g. Pap test, visual inspection with acetic acid (VIA), clinician-collected HPV testing) (RR: 2.13, 95% CI=1.89 to 2.40). The size of the effect varied by HPV test kit dissemination method, whether mailed directly to home (opt-out strategy) (RR: 2.27, 95% CI=1.89 to 2.71), offered door-to-door (RR: 2.37, 95% CI=1.12 to 5.03) or requested on demand (opt-in strategy) (RR: 1.28, 95% CI 0.90 to 1.82) (Yeh et al., 2019).

In the specific case of immigrant populations, HPV self-sampling interventions have been reported to be “promising” in increasing CC screening uptake (Alam et al., 2023). For instance, in a study conducted with Somali immigrants, participants in the HPV self-sampling group were 14 times more likely to complete the CC screening test compared to those in the Pap test group ($P = 0.0002$) (Sewali et al., 2015). However, as with any other public health intervention, assessing acceptability and feasibility prior to implementation is crucial. According to various literature reviews (Narvaez et al, 2023; Nishimura et al., 2021; Marshall, Vahabi and Lofters, 2019; Morgan et al., 2019; Braz et al, 2017), overall, immigrant and non-immigrant women are receptive to HPV self-sampling. Different motivators explain women’s preference for self-collection over clinician-based CC screening, however, self-sampling poses its own barriers as well.

2.6.1 Motivators to use HPV self-sampling

Women’s CC screening preferences are influenced by multiple factors, such as age, education, socioeconomic status, country of origin, religion (Drysdale et al., 2022; Hamdiui et al., 2022a; Tisci et al., 2003). For instance, in a study conducted in the UK, self-sampling was more frequently preferred by the highest occupational grade and older women, while it was less popular among ethnic minority groups (Drysdale et al., 2022).

Regarding the motivators to use self-sampling, physical comfort, privacy and convenience were the most common advantages mentioned by immigrant women. Women in the Netherlands emphasized that self-sampling eliminated the pain and discomfort that comes with the pelvic examination during a Pap test (Hilverda, Fissers and Van den Broek, 2021) and a significant proportion of women in studies conducted in the Netherlands and Canada highlighted the confidentiality and privacy that self-sampling offers. They valued being able to collect the sample in the privacy of their homes and send the sample without even family members being aware (Devotta et al., 2023; Hilverda, Fissers and Van

den Broek, 2021; Vahabi and Lofters, 2016). For instance, some immigrant women in Canada mentioned the benefit of this method for undertaking screening among Muslim women who were sexually active prior to marriage (Vahabi and Lofters, 2016). Pre-marital sexual activity is a cultural taboo in Muslim communities with severe consequences that can include being disowned by one's parents. Therefore, this approach has been found to allow sexually active unmarried Muslim women the opportunity to participate in CC screening without their families' knowledge (Vahabi and Lofters, 2016).

Many women also mentioned that self-sampling offered a solution for modesty, embarrassment and shame issues towards healthcare providers (especially males) (Hamdiui et al., 2022a; Barbee et al., 2010). For instance, a participant in the Netherlands believed that self-sampling is *halal* (i.e. pure and allowed by the Quran) mainly because they did not have get in touch with anyone and it did not need to expose their body to a doctor (or anyone else) (Hilverda, Fissers and Van den Broek, 2021). The convenience of not having to arrange a medical appointment to get screened was also valued by women in Ontario, Canada, who considered self-sampling to be cost-effective and time-saving since they did not have to take time off work or pay for childcare and transportation (Vahabi and Lofters, 2016). Similarly, in the study conducted with Haitian immigrant women in Miami (US), participants emphasized that self-sampling addressed critical access barriers, including poverty and language difficulties (Barbee et al., 2010).

2.6.2 Barriers to use HPV self-sampling

In most studies conducted with immigrant women, the concern of not being able to correctly perform the self-sampling was present (Devotta et al., 2023; Adegboyega, Desmennu and Dignan, 2022; Hamdiui et al., 2022a; Marshall, Vahabi and Lofters, 2019). Haitian immigrant women in the US were concerned that they might not be sampling from the right place and expressed that they had more confidence in their doctor's ability than their own to get adequate samples for cytology and HPV testing (Barbee et al., 2010). Because of this low self-efficacy, immigrant women in the US and the Netherlands distrusted the accuracy of the CC test results (Adegboyega, Desmennu and Dignan, 2022; Hamdiui et al., 2022a). Interestingly, in the literature review conducted by Marshall, Vahabi and Lofters (2019) those immigrant women who tried HPV self-sampling considered it easy to use; they indicated not having difficulties to follow the instructions and that they would recommend it to family and friends. As facilitators for HPV self-sampling use, in a study with immigrant women in the Netherlands, participants indicated that they would be interested in self-sampling if their primary care doctor showed them how to do it or had video tutorials instead of written information with pictures (Hamdiui et al., 2022a).

Cultural barriers were also reported in different studies. For instance, Moroccan and Turkish women in the Netherlands expressed their concern about the possibility of self-sampling to affect virginity (Hilverda, Fissers and Van den Broek, 2021), whereas other immigrant women expressed unfamiliarity with their own bodies: for instance, Chinese participants in Canada were reluctant to perform the self-sampling procedure because of issues related to a lack of use of tampons in their community (Howard et al., 2009). Another issue identified in the literature was the cost associated with HPV self-sampling. In Canada, since HPV self-sampling is not part of the public CC screening guidelines, immigrant women stated that if they had to pay out of their own pocket then the cost would become an important factor for not undertaking the test (Vahabi and Lofters, 2016). Finally, Marshall, Vahabi and Lofters (2019) in their review concluded that overall immigrant women globally preferred to have the choice of HPV self-sampling, but would like it to be optional alongside conventional CC screening (e.g. Pap smear).

2.7 Research gaps

Despite much literature on the barriers and facilitators to CC screening and acceptability of HPV self-sampling among immigrant women, I identified some key research gaps. Most existing evidence is based on studies conducted in the US, Canada, Australia, UK and mainly Scandinavian European countries and targeting specific immigrant communities, including Hispanic/Latina, Vietnamese, Chinese, Somali, South Asian and Russians. Although in neighbouring countries with similar migrant dynamics, such as Portugal, a few qualitative and quantitative studies on barriers and facilitators to CC screening have been identified (Marques et al., 2020, 2023), as mentioned in the introduction, to the best of my knowledge, no qualitative study has addressed the individual, social and health system determinants of CC screening behaviours and acceptability of HPV self-sampling among immigrant populations in Spain. Additionally, research focused on Moroccan immigrant women is almost non-existent, except for two studies conducted in the Netherlands, and the evidence on Pakistani women is mainly from studies in which different South Asian ethnic groups were mixed (e.g. Indian, Pakistani, Bangladeshi) and in which Pakistani participants were often underrepresented, except in a few studies conducted in Norway and the UK.

Taking into account that women's behaviours and understandings of disease and symptoms are products of their social and cultural contexts, beliefs, life experiences and other socioeconomic factors, existing evidence may not be generalizable to all ethnic groups and settings. This is especially relevant for immigrant women from Morocco and Pakistan living in Catalonia, Spain, as their health belief systems may differ from the host country, as well as their health expectations and interactions with the Catalan health system. Therefore, more research is needed on non-Western immigrant

women living in European countries, in this case, the specific context of Spain, historically a country of emigration which in recent decades has become in a major immigrant destination.

Finally, although community-based, participatory and culturally tailored interventions seem to be the most effective approaches to increase CC screening uptake and the use of HPV self-sampling, it is important to mention that the evidence is mainly based on interventions located in the US. More interventions and trial evaluations are needed outside the US context, especially in Europe, to evaluate the effectiveness of these approaches.

My work will fill several of these gaps by providing a multi-level analysis addressing knowledge and perceptions of Moroccan and Pakistani immigrant women about CC and HPV screening, potential social influences on women's self-care and preventive health behaviours, and health system barriers, such as communication challenges between immigrant patients and healthcare providers, and by assessing the acceptability of HPV self-sampling among these two groups of women.

Chapter 3 Theoretical frameworks and models informing this thesis

Different conceptual frameworks and theories informed the development of this thesis. First, the thesis aimed to comprehensively explore the determinants of immigrant women's CC screening behaviour and was guided by an adapted version of the ecological framework for health promotion programmes proposed by McLeroy et al. (1988). Under this ecological framework, the multi-level analysis (individual, interpersonal/community and health system level determinants) drew on a range of theoretical approaches, including the health belief model (HBM) and the theory of planned behaviour (TPB), social norms and social network theories, the theoretical framework to assess acceptability of health interventions proposed by Sekhon, Cartwright and Francis (2017) and Betancourt et al.'s (2003) cultural competence model. In this Chapter, I describe each of these frameworks and theories, followed by a brief discussion on the rationale for using them, where in the thesis I applied them and their purpose.

3.1 Ecological model for health promotion programmes

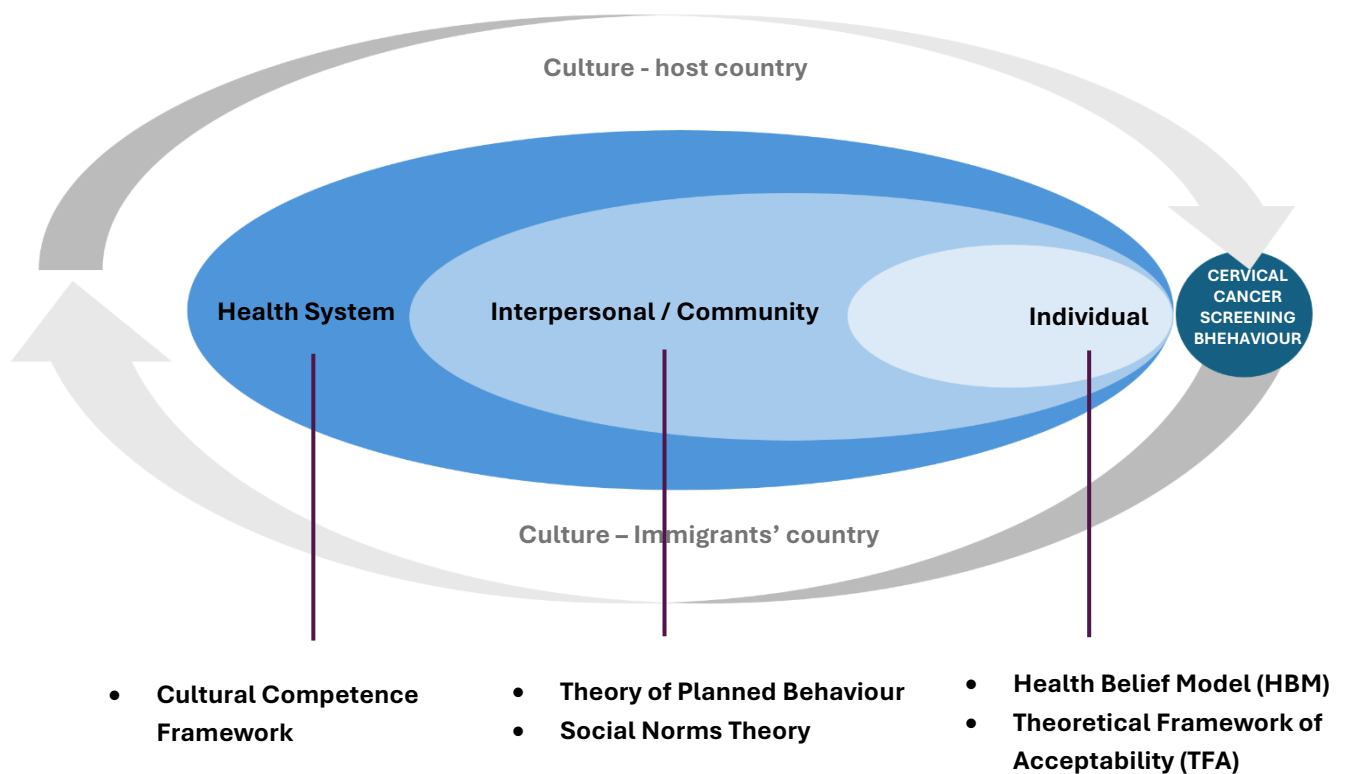
The ecological model for health promotion programmes adapted by McLeroy et al. (1988) from the one originally proposed by Urie Brofenbrenner (1979, 1977), is a response to the 'victim-blaming ideology' which holds individuals responsible for their own health behaviours (e.g. lifestyle) and health status (e.g. disease) ignoring "*the crucial connection between individual behaviour and social norms*" (Tesh, 1981, page 379) and, thus, "*neglecting the social causation of disease*" (Sloan, 1987). As opposed to individual health behaviour change interventions, McLeroy et al.'s (1988) socioecological model (SEM) focuses attention on both individual and social environmental factors as targets for health promotion interventions, reflecting the ecological view that behaviour both affects, and is affected by the social environment. In this model in particular, behaviour is viewed as determined by interrelated factors at intrapersonal, interpersonal, institutional, community and public policy levels; hence interventions addressing these multiple-level factors are proposed. This model also emphasizes the importance in taking context into consideration in identifying 'hard-to-reach populations' and, subsequently, address health disparities:

"The extent to which health promotion focuses on individuals and individual choices and ignores the social and organizational context of health-related behaviours may also affect the extent to which we are able to reach specific groups in society" (McLeroy et al., 1988).

Based on the above principles and targets, for my thesis I adapted McLeroy et al.'s (1988) ecological model to investigate the interrelated determinants of CC screening behaviours among Moroccan and

Pakistani women living in Catalonia, Spain, at individual, interpersonal/community, and health system levels and I added a macro level reflecting culture as a determinant of health and, specifically showing how the culture of immigrants and the culture of the host country filters down across the mentioned ecological layers (individual, interpersonal and health system). For each level, I applied different behavioural and social theories. See the adapted conceptual framework, including the theories applied in each analysis level, below (Fig. 2) and the complete conceptual framework developed as a result of the study fundings in Chapter 9, Fig. 7.

Figure 2 Conceptual framework adapted from McLeroy et al. (1988) and theories applied at each level of analysis.



This socioecological model is an appropriate conceptual approach for a comprehensive analysis of the barriers and facilitators to CC screening, particularly regarding HPV self-sampling.

3.2 The health belief model and the theory of planned behaviour

Social cognition models of health behaviour have been extensively used to explain the determinants of behaviour patterns. These frameworks postulate that, in addition to sociodemographic characteristics and knowledge, personal beliefs and attitudes of the individual are important determinants of preventive behaviour (Dsouza et al., 2022b; Soskolne, Marie and Manor, 2007).

One of the most widely used conceptual frameworks in health behaviour research is the health belief model (HBM), developed in the 1950s (Hochbaum, 1958; Rosenstock, 1960, 1966, 1974). This model assumes that the probability of performing a certain behaviour increases when individuals believe that: they are at risk of developing a given disease or condition (perceived susceptibility); the consequences of the disease are severe or life-threatening (perceived severity); the behaviour is beneficial and the barriers are few (perceived benefits and barriers), and when they feel that they are capable of performing the behaviour (self-efficacy) and they respond to stimulating prompts to perform the behaviour (cues of action) (Rosenstock, 1974).

Despite its extended use, the HBM primarily emphasizes individual perceived beliefs and neglects important social factors, such as social norms (VanLandingham, Suprasert and Grandjean, 1995), which have been incorporated into other well-known behavioural theories, such as the theory of planned behaviour (TPB). This model, developed by Ajzen (1985, 1991) as an extension of the theory of reasoned action (TRA) (Ajzen and Fishbein, 1980), postulates that individuals are more likely to perform a certain behaviour if they have the intention to do so, and that this intention is influenced by a set of behavioural beliefs, for instance, about the benefits of the behaviour (attitudes), along with the perception that the behaviour is supported by significant others (subjective norms) and the belief that one is capable of performing it (perceived behavioural control) (Ajzen, 1985, 1991). The emphasis on norms adds a culturally based perspective of behaviour and the intention includes the most proximate determinant of behaviour.

Acknowledging the overlap of some of the constructs of both models and the benefits of their unique components, studies have recommended the combination of both models, especially, their adaptation to traditional, non-Western populations, and have empirically demonstrated its benefits (Soskolne, Marie and Manor, 2007). Based on these recommendations and empirical results, I combined interrelated constructs from the above two behavioural models throughout the thesis: personal beliefs and perceptions (e.g. perception of risk of HPV infection and CC, beliefs about CC screening), self-efficacy (e.g. to perform HPV self-sampling correctly) and social norms (e.g. the influence of strong and weak ties) in order to analyse Moroccan and Pakistani women's CC screening behaviours.

3.3 Social norms and social network theories

“Being human is to be social, and to be social is to influence and be influenced by others” (Forgas and Williams, 2001). Social norms theory is a theory of social influence that explains the mechanisms through which individuals’ behaviours are influenced by what others do, or by what others think. Through social interactions, observations and information, people form opinions and beliefs about how they should behave and about what is socially acceptable (Forgas and Williams, 2001). Social norms theory distinguishes between two types of norms: beliefs about what others will approve or disapprove of in a given situation (injunctive norms) and beliefs about what others do in a given situation (descriptive norms) (Cialdini, Kallgren and Reno, 1991; Cialdini et al., 2006). For instance, social norms about a health behaviour (e.g. getting screened for CC, vaccination) – whether accurate or not – can act as a form of social influence if individuals adopt the behaviour because they perceive that this is approved of by their social reference group (injunctive norms) (Griva, Anagnostopoulos and Madoglou, 2010) or because they perceived that relevant peers adopt the behaviour (descriptive norms) (Allen, Stoddard and Sorensen, 2008). The creation and transmission of social norms occurs within individuals’ social networks, i.e., all social relationships that people have (Thoits, 2011). Social network theory postulates that social networks, both strong (i.e. family, friends) and weak (i.e. colleagues) may also influence and predict health behaviours and outcomes (Lin et al., 2019; Granovetter, 1973). In sum, these two interrelated theories assume that individuals’ behaviours are likely to be influenced both by strong and weak ties through both injunctive and descriptive norms.

Social norms theory informed the development of the qualitative research tools and the social network analysis protocol used throughout the thesis. In Chapter 5, I explore how social norms influenced self-care and prevention attitudes and practices among Moroccan and Pakistani immigrant women. In Chapter 6, social norms and social network theories inform the egocentric social network analysis conducted among 22 participants, by exploring the characteristics of women’s social networks and the role of strong and weak ties on their CC screening behaviours, as well as the potential influence of subjective (i.e. perceived proportion of contacts who recommended women to get screened for CC) and descriptive (i.e. perceived proportion of female contacts who were actually screened) norms. In Chapter 7, I explore how social norms may hinder patient-provider relationship by confronting different cultural understandings and expectations of healthcare provision (i.e. same sex of the provider, provision of specific SRH services). Finally, in Chapter 8, social norms are analysed in relation to women’s motivators and barriers to use HPV self-sampling.

3.4 Cultural competence frameworks

An important component of access to healthcare for culturally diverse populations is the cultural competence of healthcare systems (Anderson et al., 2003). A commonly used definition of cultural competence (interchangeably used with cultural competency) is “*a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals; enabling that system, agency or those professionals to work effectively in cross-cultural situations*” (Cross et al., 1989). Cultural competence goes beyond cultural awareness or sensitivity and the mere acquisition of knowledge about different cultural perspectives. It implies having skills and being able to use them effectively in multi-cultural environments. The term ‘cultural competence’ has been also used to refer to the institutionalisation of appropriate practices and policies for diverse populations (Brach and Fraserirector, 2000).

A number of frameworks have been proposed in the last two decades aiming to improve the cultural competence of the health systems and reduce health disparities among immigrant populations. Betancourt et al.’s (2003) framework identified three main levels of healthcare delivery where sociocultural barriers may occur and cultural competence interventions may be developed to overcome these and improve healthcare access among minority populations: organisational (i.e. related to diverse leadership and workforce), structural (i.e. related to interpreter services) and clinical (related to patient-provider relationship) levels.

In Chapter 7, I describe the communication barriers due to language limitations and cultural differences between Moroccan and Pakistani immigrant women and healthcare providers and I adopt Betancourt et al.’s (2003) framework healthcare delivery levels to categorise the barriers identified during data analysis and propose specific cultural competence interventions in each level.

3.5 Theoretical framework of acceptability

Assessing acceptability is a critical step for the design, implementation, and evaluation of healthcare interventions. Successful implementation depends on the acceptability of the intervention to both intervention deliverers (e.g. researchers, healthcare providers) and recipients (e.g. patients) (Diepeveen, et al., 2013). The definition and operationalisation of this construct is complex. Within the healthcare literature, various definitions have been proposed. Sekhon, Cartwright and Francis (2017) reviewed these definitions and proposed a common theoretical framework to assess acceptability in public health interventions. They defined acceptability as “*a multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to*

be appropriate, based on anticipated or experience cognitive and emotional responses to the intervention”.

Qualitative (Ayala and Elder, 2011) and quantitative (Tatar et al 2023, Bartlett et al 2021a) methods have been used to examine acceptability. Based on their robust review on acceptability research, Sekhon, Cartwright and Francis (2017) propose a theoretical framework to inform assessment tools and evaluations of the acceptability (TFA) of new or existing interventions. The TFA identifies seven different components: affective attitudes (how an individual feels about taking part in an intervention); burden (the perceived amount of effort that is required to participate in the intervention); ethical concerns (the extent to which the intervention has good fit with an individual’s value system); intervention coherence (the extent to which the intervention the participant understands the intervention and how it works); opportunity costs (the extent to which benefits, profits, or values must be given up to engage in an intervention); perceived effectiveness (the extent to which the intervention is perceived as likely to achieve its purpose) and self-efficacy (the participants’ confidence that they can perform the behaviour(s) required to participate in the intervention).

In Chapter 8, I assess the acceptability of HPV self-sampling among Moroccan and Pakistani immigrant women using a mixed-methods approach. The findings that emerge from the qualitative data analysis using inductive and deductive approaches, are organised according to each of the above dimensions (see Table 19).

Chapter 4 Methods

My thesis is characterised by applying a multidisciplinary approach, which combines knowledge and skills from several academic disciplines (Choi and Pak, 2006) to better understand a complex phenomenon, such as individuals' health behaviours. Literature on a range of social and health science disciplines, such as social and health psychology, medical sociology and anthropology, epidemiology and public health informed my study. The presence of epidemiologists, community health practitioners from Morocco and Pakistan and social scientists in the research team also reflected this multidisciplinary approach. Moreover, I consulted studies on migrant health, specially focused on Moroccan and Pakistani women in order to gain contextual insights about these two migrant populations. Using this multidisciplinary lens, I designed a qualitative-driven mixed-methods embedded research study (Creswell, 2003; Creswell et al., 2003; Morse and Neihaus, 2009), guided by my constructivist and transformative orientations. A human-centred approach and narrative-based techniques also guided data collection and analysis for this study.

All these interrelated research grounds are discussed below: my epistemological positions (4.1), the research approach applied throughout the thesis (4.2) and the study design and rationale for choosing specific data collection methods (4.3). I then provide an explanation of the development of the research materials (4.4) and analysis approaches (4.5), and finally, I include two sections concerning the reflexivity of the researcher (4.6) and ethical considerations (4.7).

4.1. My epistemological positions

In contrast to the (post)positivist approaches which believe in a 'single reality' independently of our beliefs and constructions, my philosophical assumptions draw on the social constructivist epistemology, which rejects the idea of one objective, universal, knowable 'truth', in favour of multiple, subjective realities constructed through our lived experiences and interactions with others (Hudson & Ozame, 1988; Lincoln and Guba, 2000) and therefore, different for everyone. For instance, in a cost-of-living crisis the challenges that two PhD students from a 'working-class' family and 'upper-class' family face are essentially different and, therefore, the subjective experience of the doctoral journey is unique to each person. Social constructivists assume that understanding these social realities can only take place through the interpretation of its participants' narratives (Denzin and Lincoln 2011; Bryman, 2004). Therefore, the goal of research is to rely as much as possible on the participants' views or interpretations. Since constructivist researchers recognize that their own background and experiences also shape their interpretations, findings are co-constructed between the researcher and the researched and shaped by individual experiences (Creswell, 2003). As a researcher,

I acknowledge that my way of interpreting the world is influenced by my status as an immigrant from Spain to the UK, but still belonging to a white minority world culture, and by my social justice and women's rights advocate position. Therefore, in this study in particular, I played a "cultural outsider" role, which I discuss below (section 4.6).

The transformative (critical) paradigm agrees with the above constructivist viewpoint that multiple realities are socially constructed, but it considers it essential to acknowledge that these different realities can emerge because different levels of 'unearned privilege' are associated with characteristics of participants and researchers (e.g. social, political, cultural, economic, ethnic, racial, gender, age, and disability values) (Mertens, 2007). According to this epistemological paradigm, knowledge is socially and historically located within a complex cultural context. Respect for culture and awareness of power relations is critical. These transformative philosophical assumptions provide a framework "*for addressing inequality and injustice in society using culturally competent, mixed methods strategies*" (Mertens, 2007), which is aligned with the aims of this thesis.

Maxwell (2013) does not believe that researchers need to adopt a single epistemology, but that aspects of different paradigms can be combined as long as these are compatible. Under this principle, Kincheloe & McLaren (2004) propose 'bricolage' as a research strategy that addresses the complexity of the lived world and allows for interdisciplinary contributions. As a bricolage of the above two paradigms, this thesis adopts a transformative constructivist lens and a mixed-methods approach to address health inequities in CC prevention programmes among immigrant populations in Spain. Using the case of Moroccan and Pakistani immigrant women, I qualitatively explore barriers and facilitators to CC screening through the experiences and views of immigrant patients and healthcare providers. I also incorporate quantitative methods: first, to analyse the composition of participants' social networks and subjective norms, and how these could affect women's CC screening behaviours and second, to evaluate the acceptability of HPV self-sampling, as a potential solution to the above screening inequities.

4.2 Research approach

Two main research approaches inspired this mixed-methods study: a human-centred and a narrative-based technique approach. I will discuss each of these approaches below and the rationale for adopting them in this study.

4.2.1 Human-centred design approach

My thesis draws on the underpinnings of the human-centred design (HCD) approach, which involves an effort to perceive a problem and/or solution from the perspective of the target user as the qualitative research studies frame an issue as they are understood by people themselves (Lubis and Shahri, 2022). Three main objectives are highlighted within the HCD approach: enhancing human abilities, overcoming human limitations and fostering user acceptance (Rouse, 1991). In the field of public health, this approach is therefore commonly used to engage stakeholders (e.g. patients, healthcare providers) in the design and/or evaluation of interventions to meet their specific needs (Lubis and Shahri, 2022). Studies have demonstrated that using HCD approaches when developing health interventions can improve health outcomes in diverse populations (Koehly et al., 2015; Parmar, 2010; Catalani et al., 2014) and when developing solutions may result in increased uptake of services (Itad, 2017). This may be because HCD allows a better understanding of people's needs, expectations and experiences, and more culturally-driven and contextually-appropriate solutions or interventions (Barlett et al., 2021b). In sum, as Barlett et al. (2021b) emphasize, addressing public health problems through an HCD approach is not only more ethical, but also more effective in creating solutions for populations that are more likely to experience disadvantages.

My qualitative exploratory research aimed to help inform the design of future interventions hoping to increase CC screening uptake among immigrant women, as in this case, from Morocco and Pakistan. Particularly, the study sought to evaluate the appropriateness of implementing HPV self-sampling as a primary self-collection method to CC screening 'with' - instead of 'in' - these two populations. Based on the HCD approach, we (I will adopt an inclusive voice ('we') in this chapter to reflect the engagement of the fieldwork team during data collection) sought not only to capture Moroccan and Pakistani participants' experiences and views on CC screening, including HPV self-sampling, but more importantly to identify their needs in their own voices and take note of their recommendations for the implementation of the overall CC screening programme in Catalonia. Ultimately, we sought to empower participants and their female contacts by giving them accurate information in order to make informed decisions and we facilitated a safe space during the FGDs to share with other women their experiences, ideas and concerns regarding CC.

4.2.2 Narrative-based techniques

Telling stories is a natural way of explaining our experiences to others. Narrative (storytelling) is a powerful tool for illuminating and reporting the cultural contexts of health (meaning practices and behaviour that groups of people share and which are defined by customs, language and geography) (Greenhalgh, 2016). Storytelling has been used as a research method or tool in public health to elicit

information (e.g. people's personal stories of real-life or authentic experiences around public health issues) and/or as an intervention to behaviour change in relation to public health issues, with special attention to those with a strong element of disease prevention (e.g. using stories to clarify misinformation and enhance learning around the importance of screening) (McCall et al., 2019).

In this study, I adopted a storytelling approach as a complementary tool to traditional qualitative research methods. Particularly, I used the vignette technique within the focus groups. Vignettes have been defined as "*short stories about hypothetical characters in specified circumstances, and the interviewee is invited to respond to those situations*" (Finch, 1987). Vignettes can adopt different formats (e.g. text, images, video) and have been used in both quantitative and qualitative studies. However, their use is more convenient in qualitative research, especially to address sensitive topics (Erfanian et al., 2020). Vignettes are often of great help to participants to express their opinions and stories in a focus group and discuss with each other. Participants are usually asked to respond to a particular situation from the viewpoints of the vignette characters, from their own point of views or discuss the probable reaction of peers. Thus, they feel more comfortable and less threatened when expressing their real opinions or speaking about their own situation and actions since they feel it is not personal (Gourlay et al., 2014; Brondani et al., 2008; Hughes and Huby, 2002).

Since the topic of my research is highly sensitive, I used a fictional story of an immigrant woman, called Fatima (a common name both in Morocco and Pakistan) and with the median age of the participants (41 years old), who was diagnosed with CC. The complete narrative is shown in section 4.4.4. The story served as an introduction to the topic of cancer and guided the group discussion to the end. It helped participants engage with the topic, freely sharing their opinions about Fatima, other women's cases, as well as their own personal experiences. For instance, some participants in both cohorts shared their own experiences of cancer leading to emotional reactions and supportive gestures from the group.

The storytelling approach facilitated a trusting space where women also felt more comfortable to talk about their self-care attitudes, share their screening experiences and perceptions about their relationship with the healthcare providers, as well as to learn from each other. The fictional character, Fatima, became a 'real' participant within the groups. Women developed strong empathy with her case and in all groups some women even asked whether Fatima responded to the treatment or not, suggesting the powerful effect of storytelling techniques not only as an effective tool to extract data, but also to motivate and persuade individuals towards behavioural change (Brooks et al., 2022; McCall et al., 2019). For instance, narrative techniques have been used to increase breast cancer screening and improve smoking cessation among African-American populations in the US (Williams-

Brown, Baldwin and Bakos, 2002; Cherrington et al., 2015). Details on the design and questions associated to the vignettes are explained in section 4.4.4.

4.3 Study design

4.3.1 Description of the study design

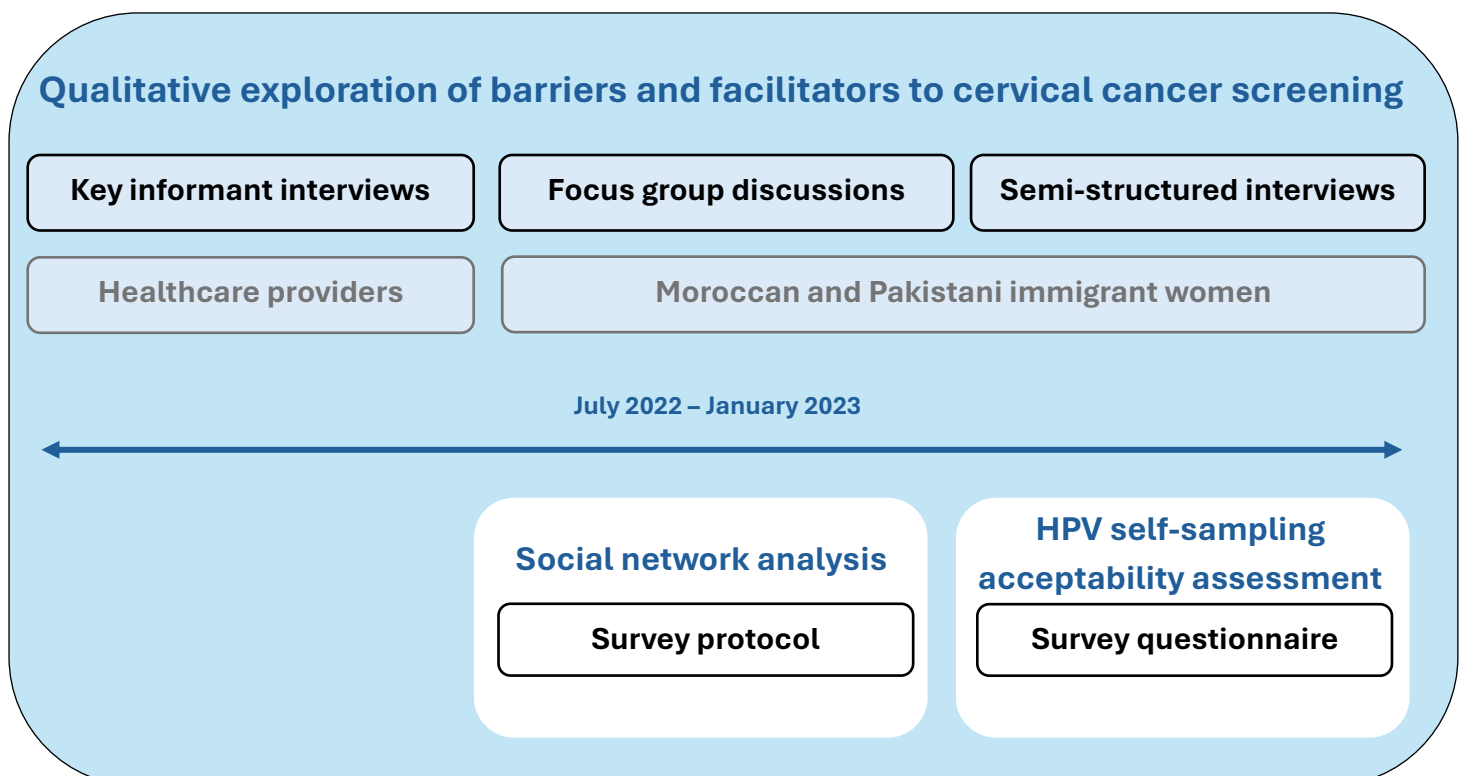
Consistent with the above epistemological positions, I designed a qualitative-driven mixed-methods embedded research study (Creswell et al., 2003; Morse and Neihaus, 2009), which consisted of an exploratory, descriptive qualitative study, and two quantitative surveys. Table 3 shows the research questions with the corresponding methods used to address them and Figure 3 illustrates visually how the quantitative methods (social network analysis and acceptability survey) were embedded into the main qualitative study.

Table 3 Research questions and methods.

Research questions	Research methods
RQ1. What are the knowledge and perceptions of Moroccan and Pakistani immigrant women about CC and HPV, and screening programmes in Catalonia, Spain?	<ul style="list-style-type: none"> • Focus group discussions • Semi-structured interviews
RQ2. How do social networks influence Moroccan and Pakistani immigrant women’s preventive health behaviours, and specifically, their participation in CC screening programmes?	<ul style="list-style-type: none"> • SNA survey protocol • Semi-structured interviews
RQ3. What are the main challenges to the accessibility and provision of SRH services, especially CC screening, to immigrant women in Catalonia, Spain?	<ul style="list-style-type: none"> • Focus group discussions • Semi-structured interviews (women) • Key informant interviews (healthcare providers)
RQ4. Which strategies are more suitable to increasing Moroccan and Pakistani immigrant women’s CC screening uptake? Specifically, what are the opportunities and challenges of HPV self-sampling as a primary sample collection method for CC screening?	<ul style="list-style-type: none"> • Focus group discussions • Semi-structured interviews • Socio-demographic survey • Acceptability survey

“Understanding the richness and complexity of human behaviour is the crux of qualitative research” (Renjith et al., 2021). In healthcare, qualitative research is widely used to understand patterns of health behaviours, describe lived experiences, develop behavioural theories, explore healthcare needs, and design health interventions (Renjith et al., 2021). Since the aim of this study was to help inform the adaptation of CC screening programmes and/or design of future interventions to increase CC screening uptake among immigrant women, an exploratory, descriptive, qualitative study (McCall et al., 2019; Greenhalgh, 2016) was designed. This research approach allowed to capture immigrant women’s self-care and prevention attitudes, personal experiences with CC screening, as well as cultural, social and structural factors influencing their screening behaviours. I used a multi-method qualitative design, combining different sources of information (e.g. Moroccan and Pakistani immigrant women and healthcare professionals) and research methods (FGD, SSI and KII) aiming to collect richer data and gain a more comprehensive understanding of women’s self-care practices and preventive health behaviours (e.g. CC screening), as well as other barriers to accessing prevention services.

Figure 3 A qualitative-driven mixed-methods embedded study design guided this thesis.



Social Network Analysis (SNA) is defined as a set of methods used for mapping, measuring and analysing social interactions between individuals, groups and organizations (Scott, 1999; Borgatti et al., 2009). In public health, SNA has been used to study: the influence of social networks on health behaviour; the role of social support networks on mental and physical health; the disease transmission and information transmission pathways (Luke and Harris, 2007). There are two main SNA research designs: sociocentric and egocentric. Sociocentric network analysis focuses on the pattern of relations within a socially defined group (e.g. members of a religious organisation or school class); egocentric network analysis focuses on each individual's personal networks across multiple social settings, generating a set of networks, one for each 'ego' (the person of interest) (Perry, Pescosolido and Borgatti, 2018).

Since my objective was to explore the personal relationships of Moroccan and Pakistani immigrant women individually and to identify potential social influences on women's screening behaviours, I designed an egocentric social network analysis study, combining numeric data, network graphs and qualitative interview data, to describe the structure (size, composition, density) of 22 participants' networks (see Appendix 8), explore health information transmission and perceived support, and to identify whom in their networks could play a constraining or facilitator role in women's self-care and CC screening behaviours.

Finally, as an experimental strategy to assess the acceptability of HPV self-sampling offered in a particular invitation scenario (e.g. face to face in group invitations), we provided a self-administered survey after offering two different HPV self-sampling devices to all the participants who took part in the FGDs and in the SSIs. The survey questionnaire was then completed by those participants who accepted the invitation and a sheet of paper with one question asking the reasons for not using the devices, was also provided to all participants.

4.3.2 Rationale for a qualitative-driven mixed-methods study

Qualitative-driven mixed-method studies are those that incorporate a core qualitative project complemented by supplemental quantitative components or those that incorporate two qualitative approaches in the same study (Morse and Niehaus, 2009). These types of studies often use embedded designs, which occur when the researcher add a quantitative strand within a qualitative design or vice-versa (Carecelli and Greene, 1993; Greene, 2007). A variety of reasons for mixing methods is found in the literature (Bryman, 2006), which can be summarized in five: triangulation, complementarity, development, initiation and expansion (Greene, Caracelli and Graham, 1989).

In my thesis, I embedded two quantitative supplemental surveys to strengthen the core qualitative study design and provide stronger evidence in relation to the influential role of the social networks on participants' health behaviours, as well as their acceptability of HPV self-sampling. Therefore, the rationale for 'mixing' methods responded to triangulation, seeking corroboration from different methods, but also complementarity, seeking enhancement and illustration of the results. For instance, the HPV self-sampling acceptability survey allowed me to corroborate the participants' preference for clinician-based screening over self-sampling, while the qualitative data provided the potential reasons of this preference (e.g. lack of confidence to perform the HPV self-sampling). In the case of the egocentric network analysis, complementary of information was sought: the SNA data allowed me to explore the participants' social network structure, while the qualitative data put 'meat on the bones' providing rich and in-depth narratives that described the transmission of health information and advice among immigrant women, as well as other social interactions, for example, with her husband.

Creswell and Plano Clark (2017) state that 'mixing' (of methods) - also refers to 'point of interface' (Schoonenboom and Johnson, 2017) - can occur at four possible points during a study's research process: at the design stage, during data collection, analysis or interpretation. In my research, the 'mixing' occurred at all these points: *At the design stage*, it was not an emergent, but a planned embedded study design, and both qualitative and quantitative research tools were informed by the same theoretical models. For example, social norms theory informed the SNA survey questionnaire and the topic interview guide.

During data collection, qualitative and quantitative data were collected concurrently. For instance, as mentioned above, all immigrant women who participated in the focus groups and interviews were invited to try two HPV self-sampling devices and complete a socio-demographic and acceptability survey questionnaires, and the SNA protocol consisted of two parts: a survey questionnaire and an SSI topic guide.

At the analysis level, I analysed the qualitative and quantitative data separately and then I used an interactive strategy of merging or triangulating the results. In the case of the HPV self-sampling acceptability assessment, I brought the qualitative and quantitative findings together and compared them exploring convergence and divergence. I addressed this analysis expecting some divergence due to potential social desirability bias: women might have expressed positive attitudes towards HPV self-sampling - aligning themselves with more 'Western' practices - during the qualitative data collection and later, decline the invitation to try the self-sampling devices. The data sets from the social network analysis complemented each other, as explained above.

Finally, *at the interpretation point* of the research process, the rationale for ‘mixing’ was to bring together qualitative and quantitative insights aiming to gain a more comprehensive understanding of the determinants influencing participants’ CC screening behaviours. This corresponds to the ‘complementary’ rationale proposed by Greene, Caracelli and Graham, (1989).

4.3.3 Rationale for using multiple qualitative methods and sources of information

The combination of multiple qualitative research methods (FGDs and SSIs) responded to three main reasons: 1) to facilitate the recruitment of participants giving them the opportunity to choose the way in which they would feel more comfortable participating in the study, individually or in a group session; 2) to get a more inclusive sample, reaching Moroccan and Pakistani participants whose characteristics might not fit into the social norms of these two communities, for instance, younger immigrant women who may not be married or not having children, and, thus, they could decline to express themselves in a FGD, but accept to be interviewed, and 3) to capture richer data and gain a more comprehensive understanding of women’s self-care and prevention attitudes and practices, including CC screening using HPV self-sampling.

Whereas FGDs allowed participants to interact with each other and explore, discuss, share and learn from their experiences, knowledge, beliefs and attitudes - allowing the researchers to identify social norms and shared cultural understandings and values - (Gibbs, 1997; Kitzinger, 1995), the SSIs provided participants a more intimate space to fully express themselves without fears of disapproval for not being consistent with the dominant group’s views, and allowed the researchers to collect more unique narratives (Guest et al., 2017).

The rationale to include different sources of information (immigrant women and healthcare providers) was to address the problem being studied (low screening participation among Moroccan and Pakistani women) from different perspectives within and outside the Catalan health system. While participants provided their personal views, expectations and experiences of their interaction with the health system from the patient perspective, the healthcare providers helped us to understand the challenges they face in providing care to immigrant patients and they also provided their professional views and suggestions to better implementing the newly organised population-based CC screening programme using HPV self-sampling in this Spanish region.

4.3.4 Rationale for combining network measures, graphs and narratives

As mentioned previously, egocentric network data is typically useful for examining how an individual (‘ego’) is impacted by their immediate social environment or social contacts (‘alters’) (Neal & Neal,

2017). Egocentric network data can adopt multiple forms: numeric, narrative and visual graphs. Each of these types of data is obtained using different research techniques: ‘name generators’ (questions to list or name the social contacts of one person according to specific parameters, e.g. context, frequency of interaction), in-depth or semi-structured interviews, and sociograms (diagrams of graded concentric circles, where the ‘ego’ is at the centre and contacts are placed around this according to their relevance or emotional closeness).

The combination of these different but interrelated network data sets can occur during data collection, analysis and interpretation of findings. For instance, qualitative methods have been used alongside network structure data to explore new or yet unexplored forms of networks and network practices among immigrant populations and to better understand change over time and the meanings and contents of the networks, such as the role of network members in decision-making processes (Hollstein, 2011). Qualitative methods together with visualizations have also been used to understand exchange patterns (e.g. emotional, information support) and as a strategy to validate network data. Network visualisations also enhance participants’ reflections about their own networks and allow to gain richer data (Tubaro, Ryan and D’Angelo, 2016; Belloti, 2016).

In my study, I used sociograms to better understand Moroccan and Pakistani immigrant women’s social networks; specifically, their emotional closeness towards each contact (‘alter’) and the connectedness between ‘alters’ (network density). The visual sociogram also served as a prompt for the qualitative SSIs (see details below), which allowed us to capture the participants’ perceptions about their own social networks. For instance, women often reacted with certain surprise when they saw that their networks in Spain were larger than initially perceived.

Social network graphs were mainly used for data analysis. For instance, we collected information on the number of participants’ contacts (size of network) and their attributes (e.g. gender, age, birth country, country of residency, education). I built the network graphs to visualize the different sizes of the women’s social networks and the presence of female/male, migrant contacts and Spanish contacts in each network. This allowed me to identify structure patterns (e.g. clusters, homophily) and/or network typologies, and better compare Moroccan and Pakistani women’s social networks; for instance, the connectedness between the network members (density) and other ‘alter’ characteristics dominant in the networks.

4.3.5 Rationale for combining qualitative and survey data to assess HPV self-sampling acceptability

The 2015 Medical Research Council (MRC) guidance for designing and evaluating complex public health interventions includes acceptability as a relevant construct for evaluation, and it provides examples of how patients' acceptability may be assessed quantitatively, by administering measures of acceptability or satisfaction, and qualitatively, by asking probing questions focused on understanding how they are interacting with the intervention (Moore et al. 2015).

In this study, I decided to examine HPV self-sampling acceptability among Moroccan and Pakistani immigrant women combining qualitative and quantitative methods in order to capture women's perceptions about this self-collection method prior to use the devices (prospective acceptability) through FGDs and SSIs, and to quantify the proportion of women who actually accepted the invitation to use the self-sampling devices, as well as their experience using the devices (retrospective acceptability). The incorporation of this quantitative component into the core qualitative study was an experimental approach and, sought to strengthen our findings by identifying convergence and divergence between both datasets and by providing details on the characteristics of women who accepted or declined the invitation to use HPV self-sampling. For instance, whereas quantitative data described participants' preferences about the type of sampling for CC screening, the qualitative accounts from the FGDs and SSIs elicited the 'whys' of these preferences, providing a more comprehensive acceptability assessment.

4.4 Data collection

4.4.1 Preparing data collection in the field

Recruitment of bilingual research assistants

A distinct and valuable feature of my research study was the use of multiple languages (Arabic/Darija, Urdu, Spanish, English) for data collection. This presented unique challenges in terms of availability of resources (e.g. qualified interpreters, costs), but also opportunities to ensure the inclusion of participants with language barriers, as well as those proficient in Spanish or English, and, consequently, to obtain richer data.

The choice of suitable bilingual workers can impact on the ultimate success or failure of a research project, as participants may fear disapproval or retribution after disclosing sensitive issues (Lee, Sulaiman-Hill and Thompson, 2014), for example, about having been diagnosed with HPV infection.

In this study, we searched for bilingual female RAs and collaborators of different ages, with verbal and written skills in Arabic/Darija and Urdu, and Spanish or English languages. The identification and recruitment of RAs was challenging, first, because potential candidates often had verbal, but not the written skills required to translate and transcribe the recordings of the FGDs and SSIs in Spanish or English. Second, because of the burden and commitment required for a data collection period of up to six months (including translations and transcriptions) - taking into account that most candidates had other permanent jobs. And third, because of the limited PhD budget for data collection (see Appendix 1). With the assistance of members of the Moroccan and Pakistani communities (through word-of-mouth), we identified and hired two bilingual students of Psychology, with verbal and written skills in Arabic/Darija and Spanish, and Urdu and English, respectively. They were second-generation immigrants, well connected with these two communities and advocates for improving women's health in these populations.

The final fieldwork team was comprised of these two RAs (in their mid-20s), who played an important role in the data collection (they conducted some individual interviews with Moroccan and Pakistani women, managed the logistics and took notes during the FGDs and translated and transcribed all the recordings of the FGDs and some SSIs); a Moroccan community health nurse with a Master in Public Health and an experienced Pakistani community health agent (both in their early 40s), who were responsible for the moderation of the FGDs and assisted with the participant recruitment process; two occasional supportive interpreters; an epidemiologist from ICO and another researcher from the same institution who helped with the translation and analysis of the healthcare providers' interviews, and a social and behavioural scientist from LSHTM (me) who led the design of the research tools and the trainings for the fieldwork team.

Translation of materials

Prior to data collection, I led the translation process of the research materials, which presented challenges. All the ethical documents, including the participant information sheet, the informed consent form and the confidentiality agreement, were available in four languages: Urdu, Arabic, English and Spanish. The decision to have four different versions of these documents was in anticipation of potential issues in comprehending the translations in (classical) Arabic and Urdu. Since Darija is an oral language - the Arabic dialect most spoken in Morocco, but not written or taught at schools -, we decided to translate the ethical documents into (classical) Arabic (language used at schools in Morocco) in order to meet the written consent requirements. We gave Moroccan participants this version along with the Spanish version, and we used the same procedure with the Pakistani participants who received an Urdu version and an English version of the consent documents, as team members advised that some women might comprehend written English better than written

Urdu. A medical student proficient in (classical) Arabic and the Pakistani RA were responsible for the translations.

We found the same issues with the qualitative and quantitative research tools. In the case of the FGD and SSI topic guides, instead of written translations, the Moroccan and Pakistani fieldworkers moderated the FGDs and performed the SSIs using the Spanish and English versions of the topic guide and translating directly all the questions into Darija and Urdu for the women. This required a deep revision of each item of the topic guides and a few pilot sessions, a process which is explained in detail in the following section. The same translation strategy was used to map the social network of the participants.

In the case of the self-administered questionnaires (e.g. socio-demographics and acceptability assessment): due to the limited budget and fieldwork timeline, we adopted a one-way translation approach, incorporating the revision of secondary ‘experts’ as a validity strategy (Dhamani and Richter, 2011). The same Moroccan medical student proficient in classical Arabic who translated the ethical documents, translated the questionnaires, and the Pakistani RA did the same with the questionnaires in Urdu. After this, the translations were sent for revision to ‘experts’ in the target languages and familiar with the topic area (a doctoral Pakistani colleague in Public Health at LSHTM and a Pakistani community health agent, and a Moroccan community nurse).

Trainings and pilot of the research tools

Apart from the unique challenges described above with regard to oral languages, gaining equivalence of meaning across languages is generally difficult. For example, some health concepts or terms may not exist in a language, making it difficult to convey the meaning from one language to another. People’s lives and experiences also influence the ways in which they translate and interpret the questions they ask, and the responses they are given (Squires, 2009). Thus, bilingual RAs are not neutral, but rather a participant in the research (Temple, 2002), something that needs to be taken into consideration during data collection and analysis.

With the above in mind, I made great efforts to identify and avoid potential bias among the fieldwork team when moderating the FGDs and conducting the SSIs. For instance, I piloted the interview topic guides with the fieldwork team members from Morocco and Pakistan (between July and August 2022), which allowed me not only to test their comprehension of the questions, but also to analyse their views, opinions and knowledge about the topic prior to start data collection. I also piloted the SNA survey protocol and I mapped the social network of the RAs and other members of the fieldwork team, which served as a ‘demo’ of the task that they needed to replicate with the study participants

and it also gave me preliminary ideas about the structure of Moroccan and Pakistani women's social networks.

Based on these pilot interviews with the fieldwork team, I designed a two-day intensive training session, focused especially on the discussion of the research instruments and ethical procedures. The sessions also included an introductory and comprehensive presentation on CC, HPV and screening, which was delivered by a researcher from ICO. An outline of the training contents and pilot of the instruments sessions is provided in Appendix 2.

During the training sessions, I paid special attention to ensuring that the fieldworkers were familiar with the overall purpose of the study and they understood each of the items of the FGD and SSI topic guides, and the survey questionnaires. For instance, I asked them to explain in their own words what we were trying to learn from the participants in this qualitative study and why, and I also went through each question of the topic guides and questionnaires and asked fieldworkers to explain in Spanish how they would translate the questions and what potential responses we could obtain. In the case of the FGD topic guide, I focused on the vignettes and I asked the fieldwork team for feedback on the appropriateness of the storytelling. 'Role play' activities were also included in the program in order to give the RAs the opportunity to practice how to map the social network of participants using the Network Canvas software (Complex Data Collective, 2016), and to practice the interview with one another. While the 'interviewer' practiced the interview with another member of the team, the 'observers' familiarized themselves with how to build rapport, identify 'close questions' or missed opportunities to probe further, allowing them to be more reflective in their own practice.

An important component of the training was to pilot the SSI and FGD tools with participants. We conducted these interviews in pairs: while one RA conducted the interview, the other observed and took notes to provide feedback in the post interview de-briefing session. In these sessions, I asked the RAs to evaluate themselves and reflect on what was difficult or what they would do differently next time. The pilots of the FGDs were conducted with three participants each. These women were recruited to pilot the tools using the same eligibility criteria as the rest of the participants. These pilots were useful for adjusting the timing of the topic guides and activities, as well as to test the comprehension of the questions. We also had de-briefing sessions after each pilot FGD. The contents of these pilot sessions were added for data analysis.

4.4.2 Study setting and recruitment of participants

The study population consisted of first-generation Moroccan and Pakistani women who migrated to Spain after the age of 16 (thus not exposed to Spanish public education, minimizing potential social

and cultural influences from the host country) and had lived in Spain for at least one year. This first year in the host country is an important period in the migration process, especially for settling down and re-build social networks. Thus, it was crucial to add this inclusion criteria to capture these new relationships in the social network analysis. Other eligibility criteria for the study sample were women's eligibility for CC screening: aged between 25 and 65 years old, not having a history of CC, and without learning or physical difficulties that did not allow self-sampling. During the two-day training, the four members of the fieldwork team were informed about the above inclusion criteria, and they were given a printed copy of the presentations' slides with all the study information and a sheet with detailed instructions for the recruitment. This served as a guide for them to check eligibility and recruit participants in the Moroccan and Pakistani communities. Initially, I aimed to recruit around 40 women for the FGDs, at least 16 women for the SSIs and 6 healthcare professionals for the KII. Based on previous qualitative studies, data saturation would be reached with this sample size. The possibility to recruit more participants allowed me to enhance data saturation: no new themes emerged from the data (Guest et al., 2020). See the final sample size in table 4.

The recruitment process was initially planned to be only in the neighbourhood of the Raval, Barcelona, as it is among the neighbourhoods in the city with the highest socio-economic deprivation, which has been correlated with poorer health outcomes (Colls, Mias and Garcia-Altes, 2018), and with the largest immigrant population in all of Barcelona, particularly representing Pakistani and Moroccan communities (Ajuntament de Barcelona, 2023). We decided to expand the recruitment process to other deprived neighbourhoods in Terrassa, L'Hospitalet de Llobregat and Sant Adrià del Besos, which are three neighbouring municipalities which also have a high concentration of immigrants from these two communities (IDESCAT, 2023). The decision was driven by our interest in capturing the views of Moroccan and Pakistani women living in semi-urban areas or smaller towns where the primary healthcare (PHC) services have often fewer resources (e.g. fewer health staff, no interpreter services), as well as the views of healthcare providers working in these PHC centres. We excluded neighbourhoods with low concentration of immigrants from Morocco and Pakistan because of two main reasons: 1. my research was embedded in a larger study with ICO and the interest was specifically in addressing health inequities and improving CC screening uptake in those disadvantaged neighbourhoods, and 2. logistic and timing reasons (e.g. availability of translators, contact with the communities, PhD study timeline) also prevented us from expanding the recruitment of participants to low migrant density neighbourhoods.

We used multiple strategies to recruit participants. For the FGDs and KIIs, participants and healthcare providers were recruited through purposive, convenience and snowball sampling techniques. Although we made efforts to recruit a diverse sample of women for the FGDs (based on the age, length of stay in Spain, Spanish proficiency, level of education), we also adopted a flexible approach

and recruited some participants conveniently due to the limited time for data collection and the challenges to access the target population, in this case immigrant women - often considered a ‘hard-to-reach’ population. Additional reasons to use convenience sampling to recruit participants were the limited budget and because it was a formative research, and a representative sample was not required. Regarding the snowball sampling process, we proposed participants to invite other women to participate in the study. We explained them the inclusion criteria and when women identified other potential participants in their social networks, they provided us with their phone number to contact them. In the case of healthcare providers, researchers from ICO put me in contact with one or two professionals who referred me to the rest of the providers interviewed.

For the SSIs, purposive sampling was used, as we sought maximum variability to be able to compare differences between participants’ social networks. To achieve this, I created a matrix (4x3 table) for each cohort with the characteristics (e.g. age, number of years living in Spain, education level, Spanish proficiency, marital status) of each potential participant (see matrices in Appendix 3). In this recruitment process, snowball sampling techniques were also applied (Given, 2008). The two RAs and members of the Community Health Unit of Drassanes, all of whom had Moroccan and Pakistani backgrounds, recruited participants through their networks and contacting religious and community-based associations and non-governmental organisations (NGO), where women from these countries usually attend language classes and other educational activities.

4.4.3 Overview of methods and timeline

Table 4 summarises the data collection methods used in this thesis with their corresponding sample and participants, the research team involved, timing and purpose.

Table 4 Summaries of the data collection methods used in this thesis with their corresponding sample and participants, the research team involved, timing and purpose.

Method	Research team involved	Sample	Participants	Timing	Purpose
Focus groups (FGDs) with immigrant women	Two community health professionals from Morocco and Pakistan moderated the FGDs	Women from Morocco and Pakistan, aged 25 – 65 years old, who migrated to	51 (24 Moroccan women and 27 Pakistani women)	22.9.22 – 16.12.2022	<ul style="list-style-type: none"> • To explore normative views about self-care and health prevention. • To explore knowledge and perceptions about cervical cancer and HPV, and screening.

		Spain when they were 16 or older and had been living in Spain for at least 1 year			<ul style="list-style-type: none"> • To explore potential health system barriers to access cervical cancer screening services, especially, in relation to patient-provider relationship. • To explore screening preferences and attitudes towards HPV self-sampling.
Semi-structured interviews (SSIs) with immigrant women	I conducted 9 interviews in Spanish, and the two RAs from Morocco and Pakistan conducted 7 interviews in Darija and 6 interviews in Urdu, respectively. All the interviews included the social network mapping		22 (12 Moroccan and 10 Pakistani women)	31.8.2022 – 12.1.2023	<ul style="list-style-type: none"> • To explore personal experiences and health beliefs. • To examine potential social influences on women’s self-care and prevention attitudes and practices. • To explore knowledge and perceptions about cervical cancer and HPV, and screening.
SNA survey protocol					<ul style="list-style-type: none"> • To describe the social networks of Moroccan and Pakistani women living in Spain. • To understand the influencing role of social networks on women’s CC screening behaviours.
HPV self-sampling acceptability questionnaire	This was a self-administered survey. The two RAs assisted some women to complete the survey. They and I collected the questionnaires, and	All women who participated in the FGDs and SSIs (except two)	71 (36 Moroccan women and 37 Pakistani women)	31.8.2022 – 12.1.2023	<ul style="list-style-type: none"> • To assess acceptability of HPV self-sampling. • To examine usability, trust in the test result and willingness to use self-sampling in the future.

	were responsible for quality assurance				
Key informant interviews (KIIs) with healthcare providers	I conducted all the interviews with the healthcare professionals in Spanish	Healthcare providers and intercultural mediators who work frequently with migrant populations	13 (3 gynaecologists, 5 midwives, 1 nurse, 1 GP, 1 intercultural mediator, 2 community health agents/workers from Morocco and Pakistan)	15.7.2022 – 23.3.2023	<ul style="list-style-type: none"> • To collect contextual data on interpreter services and other resources for immigrants within the Catalan health system. • To explore challenges providing healthcare services to immigrant populations. • To explore knowledge about cervical cancer screening guidelines and capture professional views on the implementation of HPV self-sampling.
Observation	RAs and me	The RAs observed and took notes during the FGDs, I also acted as ‘outsider’ observer in the FGDs		22.9.22 – 16.12.2022	<ul style="list-style-type: none"> • To understand social interactions and group dynamics among participants during the FGDs and identify potential controversial topics.

I began data collection with KIIs in July 2022. The recruitment of participants for the FGDs was delayed until the middle of September due to the summer holidays (see details of the fieldwork timeline in Table 5). In Spain, schools close for two and a half months, and the fieldwork team advised that immigrant families usually travel to their countries of origin in this period, which would complicate the recruitment process. During data collection, there were other festivities and bank holidays in Catalonia that interrupted data collection. I used these periods for preliminary analyses.

Table 5 Data collection timeline.

	2022							2023			
	M	J	J	A	S	O	N	D	J	F	M
Fieldwork preparation											
Set-up fieldwork team											
Translation of materials											
Training and pilot of instrument sessions											
Data collection											
KII with care providers (N=13)											
SSI with women (N=22)											
SNA mapping (N=22)											
FGD with women (8 groups, N=51)											
Acceptability survey with women (N=71)											

Data collection was especially challenging due to the busy schedules of participants, most of whom were housewives with children: half of the sample (49%) had three or more children. This led us to organise all the FGDs in the morning - once women left children at school - and to be very careful in not exceeding the time planned for the sessions, as we had the risk of women leaving the group discussion before it had finished. This happened in one of the groups with Moroccan women, but for other cultural reasons. We scheduled the FGD on Friday, prayer day for Muslim communities, and in Morocco it is tradition to eat couscous after midday prayers. At the end of the FGD, participants announced that they needed to leave soon as they had “to cook the couscous”. This led us to skip some questions and spend less time in the explanation of the HPV self-sampling devices, which could have affected the decision of women to try the devices and the quality of data from the questionnaires. However, the RAs followed up with the participants who took the devices home in order to help and clarify any doubts. This illustrates the importance of collecting contextual data about the life, culture and traditions of the participants prior to data collection. Similarly, the individual interviews with both Moroccan and Pakistani women were influenced by their childcare and home responsibilities. In some cases, the interviews had to be conducted over two days and there was one participant who withdrew before completing the interview because of competing time demands.

The busy schedules of participants also led us to make some changes in the research design. We had initially planned to invite all participants in the FGDs and SSIs to two final workshops (one with Moroccan women and one with Pakistani women) to present the preliminary findings and get their feedback and recommendations to improve the CC screening programme. However, after a discussion with the fieldwork team, we agreed that it was going to be difficult to reach the same participants to attend a second session. Instead, we decided to capture women's views and suggestions about the CC screening program in Catalonia during the first and only FGD sessions.

4.4.4. Materials

Qualitative data collection tools

A rigorous literature review informed the design of the three main qualitative instruments (FGD, SSI and KII topic guides) used for data collection. Each research tool included questions to address barriers and facilitators to CC screening at one or more ecological levels of analysis (e.g. individual, interpersonal/community and health system). Different behavioural and social norms theories and models (presented in Chapter 3) informed specific items in the topic guides. After drafting the research instruments, these were piloted and refined in collaboration with the fieldwork team in Barcelona. For instance, we shortened the SSI guide and simplified some of the interactive activities included in the FGD guide. As data collection progressed, the qualitative topic guides were re-refined, giving more emphasis to specific questions (e.g. women's understanding of health prevention) or incorporating emerging topics (e.g. the role of the husband in a women's access to care).

A. Focus Group Discussion Topic Guide

FGDs have been proven to be an appropriate and effective qualitative method to explore knowledge, beliefs and practices of CC screening and acceptability of HPV self-sampling across different populations and countries (Hamdiui et al., 2022a; Tatari et al., 2021; Bakiewicz et al., 2020; Megersa et al., 2020; Gele et al., 2017; Vahabi and Lofters, 2016; Modibbo et al., 2016; Teng et al., 2014). We designed a FGD guide, using vignettes and participatory exercises, which are described below.

Vignettes

For my thesis, the FGD topic guide was built around the fictional story of Fatima, an immigrant woman diagnosed with CC. The vignettes were developed based on the literature review conducted at the beginning of the study, especially looking at research papers focused on Moroccan and Pakistani women. After drafting the story, I shared it with the FGD moderators and the RAs from Morocco and

Pakistan to ensure that the character's features (e.g. name, age, marital status) and the story was culturally appropriate and it was adequately understood. Afterwards, I made the necessary changes reflecting the inputs from the fieldworkers and I piloted it with the team. The story was presented in 5 vignettes (see the entire storytelling in Table 6), each followed by one to four open-ended questions addressing knowledge and attitudes of Moroccan and Pakistani women about cancer and the importance of early detection; individual and cultural factors influencing women's screening behaviours (e.g. religion, HPV risk perception); community acceptance of HPV self-sampling and participants' perceived self-efficacy. Practical questions aiming to collect women's suggestions and opinions to improve CC screening participation, such as screening preferences and type of invitation, were also formulated (see the FGD topic guide in Appendix 4).

Table 6 Storytelling used in the focus groups with Moroccan and Pakistani women.

Vignette 1	Fatima is a 41-year-old woman, from Morocco/Pakistan who has been living in Barcelona for more than 10 years. She is married and she has 3 children aged 8, 10 and 11 years old. She was diagnosed with cancer three months ago.
Vignette 2	Fatima was diagnosed with cervical cancer.
Vignette 3	Before being diagnosed with cancer, Fatima felt healthy. He had no obvious symptoms. After having her last child 8 years ago, she did not visit a gynaecologist again, nor did she have a cytology.
Vignette 4	After 8 years, Fatima visited the gynaecologist accompanied by her sister because she had some blood loss (vaginal bleeding). During the appointment, the doctor proposed that she undertake a test to detect the Human Papillomavirus, which is the necessary cause for cervical cancer. He offered her two options: to collect the sample herself at home with a self-sampling device or have the sample collected by a healthcare professional at the health centre.
Vignette 5	Fatima decided to use the self-sample device. The test was positive (it seems that she had an infection caused by the Human papillomavirus) and a healthcare professional performed a cytology to check if there was a lesion on the cervix. After various tests, Fatima was diagnosed with cervical cancer.

This storytelling approach has been used over the last three decades to explore social norms, sensitive topics (e.g. HIV) and barriers to prevention services, to name a few (Hughes, 1998; Gourlay et al., 2014; Blum et al., 2019). In this study, this narrative technique made the topic of CC more ‘alive’ for the participants, encouraging them to freely express their views and opinions about a third person’s case, but also to talk about their own beliefs, feelings, attitudes and practices around cancer in general, and CC and screening, in particular.

Rapid visual test and barrier ranking exercise

The FGDs also included two interactive exercises: 1) a rapid visual test, in which women collectively needed to identify the cervix and other reproductive and genital organs (e.g. vagina, ovary, uterus) in a diagram. This served to introduce the topic, build rapport between the participants and explore their familiarity with the female reproductive system. And 2) a participatory barrier ranking exercise, whose aim was to assess what barriers to CC screening were the most relevant for these two groups of women. The activity consisted of a number of statements describing an attitude, belief or perception related (directly or indirectly) to CC and CC screening, and other barriers identified from the literature review (see Table 7). These were presented to the participants on small cards and they were asked to rank each of the barriers to CC screening, piling them according to their relevance and lining up the cards from most to least relevant. At the end of the exercise, the moderator and researchers assessed which barriers were in ‘the most relevant’ piles and participants discussed these barriers and how to overcome them. This activity appeared too complex for the moderators to explain to the participants and some women did not understand the instructions. Although we gained important insights from the accounts of women explaining why they chose the most relevant barriers for them and the following discussion around how to overcome these barriers, the ‘ranking’ exercise data were not used for analysis and comparison, as in some groups the data were not collected as intended.

Table 7 Barriers identified in the literature to design the ‘Barrier ranking exercise’.

Barriers	Literature references
I never heard about cervical cancer and/or screening	Hilverda et al., 2021; Chan and So, 2017, Vahabi and Lofters, 2016; Addawe et al., 2018; Gele et al., 2017
I don't really have time to do this test; I have other priorities, such as taking care of my children and work	Addawe et al., 2018 ; Grandahl et al., 2012
I'd rather not know if I have cancer	Marlow et al., 2015, Hamdiui et al., 2022, Addawe et al., 2018
I have not symptoms; I don't need to be screened	Marlow et al., 2015, Addawe et al., 2018; Gele et al., 2017; Raymond et al., 2014
I am not at risk to cervical cancer as I am in a marital relationship	Chan et al., 2019
I need to keep my virginity before I got married, so I cannot be screened	Szarewski et al., 2009; Addawe et al., 2018
Cancer is God's wish, there is nothing you can do	Hamdiui et al., 2021; Gele et al., 2017
I would never go to an gynaecology examination with a male doctor; it is against my religion	Hamdiui et al., 2021; Hilverda et al., 2021; Szarewski et al., 2009, Vahabi and Lofters, 2016; Addawe et al., 2018
I am shy to do such test, it would be too embarrassing for me	Hamdiui et al., 2021; Hilverda et al., 2021; Szarewski et al., 2009 ; Vahabi and Lofters, 2016; Addawe et al 2018
I am scared about gynaecological examinations; I heard it is painful	Szarewski et al., 2009; Gele et al., 2017; Marlow et al., 2015
I don't participate in the screening, because I don't understand the doctor's language	Addawe, 2018; Grandahl et al., 2012; Gele et al., 2017

Finally, at the end of the FGD, a short demonstration of two HPV self-sampling devices was provided to the participants, who were able to touch the devices. These were a swab (FLOQSwabs®, Copan, Italy) and a brush (EvalynBrush®, Rovers Medical, The Netherlands), both validated for HPV detection on multiple PCR-based HPV assays (Hawkes et al., 2020) (see images of the devices in Figure 4). After the demonstration, women were invited to try them at home. The FGD guide with the details of the vignette-questions, exercises and HPV self-sampling demonstration is available in Appendix 4.

Figure 4 HPV self-sampling devices offered to the participants to try at home.

FLOQSwabs®, Copan, Italy

Evalyn®Brush, Rovers Medical, The Netherlands



B. Semi-structured Interview Topic Guide

A narrative, face-to-face interview, which combined structured and unstructured questions, was conducted with 22 women, the same participants whose social networks were analysed. This qualitative interview topic guide was used after we (the RAs and I) mapped the social network of the participants, in most cases in the same session and in a few cases in too separate days to avoid participant burden.

Since this instrument was part of the social network analysis study and we were especially interested in identifying potential social influences on women's self-care attitudes and CC screening behaviours, many questions were focused on the perceptions of participants about their family and friends' awareness of cancer, cancer cases in their close circles, their views on health prevention programmes, community acceptance of HPV-based test and self-sampling method, and whether or not these close ties were supportive (e.g. whether they provided emotional support or encouraged them to do regular health check-ups) or whether or not they had a say in women's health decisions (e.g. use of SRH services). The topic guide also sought to capture the meaning that women gave to these networks and how immigrant peers exchanged health information and advice between them.

The design of this SSI topic guide was based on a previous literature review. Constructs from the HBM and the TPB (see Chapter 3) also informed some of the questions, such as those related to

perceptions of risk, relevance of screening, self-efficacy to use HPV self-sampling devices and subjective norms in relation to self-care, health prevention and CC screening.

Finally, since interviews offer a unique opportunity to capture individual stories, we also captured participants' personal experiences interacting with the health system, including patient-doctor relationship and accessibility barriers; participants' self-care and prevention attitudes and practices; participants' screening experiences and knowledge about HPV, and individual attitudes towards HPV self-sampling, as well as their suggestions to implement this self-collection method in their immigrant communities. The SSI topic guide is available in Appendix 7.

C. Key Informant Interview Topic Guide

I initially planned to conduct six KIIs with healthcare providers, community health workers (CHWs) and/or intercultural mediators aiming to gain contextual insights to help us to frame some of the key issues regarding CC screening among Moroccan and Pakistani women and to inform the FGD and SSI topic guides. In the course of the interviews, the opportunity, not only to recruit more healthcare providers through snowball sampling techniques allowed me to explore women's screening behaviours from the perspective of healthcare professionals, but also to delve into providers' perceptions, challenges and experiences providing SRH services, especially CC screening. Therefore, we decided to use providers' narratives for analysis along with the other datasets.

The KII topic guide also helped me to examine the cultural competence of the Catalan health system through the providers' narratives. For instance, drawing on cultural competence frameworks (see Chapter 3), I asked healthcare professionals about their relationship to and communication with these specific patients; how cross-cultural healthcare could be improved from their point of view and their attitudes and practices to overcome language and cultural barriers. The interviews with CHWs and intercultural mediators from Moroccan and Pakistani origin helped me to gain insights into participants' social norms and understanding of health and health prevention practices in their own countries, especially about cancer screening, and accessibility barriers in the Catalan health system. The interview topic guide was adapted for healthcare providers and CHWs and cultural mediators. Both instruments are available in Appendix 5.

Quantitative data collection tools

A. Social Network Analysis Survey Protocol

The SNA survey protocol development drew on previous literature on immigrants' social networks (Lin et al., 2020; Hall, Garabiles and Latkin, 2019; Schoenmakers, Lamkaddem and Suurmond, 2017; Kuschminder, 2016; Kim, Kreps and Shin, 2015; Li and Wu, 2010; Lubbers et al., 2007; Menjivar, 2002; Maya-Jariego, 2000) and behavioural and social norms theories (e.g. TPB). The tool (see Appendix 6) was designed with the aim of eliciting the social networks in which participants were embedded, social interaction patterns, and how these may influence their preferences, adherences to norms and health decision-making - in this case, about CC screening.

Some empirical studies place a limit on the number of contacts ('alters') named in response to 'name generators'. For example, Lubbers et al. (2007) used a fixed choice approach and limited the number to 45 'alters'. As I aimed to capture an estimation of the women's social networks' size, identify strong and weak ties (Granovetter, 1973) and get maximum variability, I decided to use the free-choice design, as proposed by Neal & Neal (2017), and apply no limit on how many 'alters' could be named. The protocol comprised seven sections, each of them with its respective rationale, which are explained in Table 8.

Table 8 SNA survey protocol and rationale of the items.

Section/Questions	Rationale
Section 1 / 1 – 15	Socio-demographic questions included common standard indicators of social integration, such as length of stay in the host country and employment status. Two items were added to identify under-screened and non-screened participants.
Section 2 / 1 - 6	To list the social network contacts, an interaction-based 'name generator' adapted from Lubbers et al.' (2007) study and a context-focused 'name generator' approach adapted from Bidart et al.' (2006) study, were combined: participants were asked to name family, friends and acquaintances to whom they had some contact in the last two years and they responded to the 'name generator' sequentially for six spheres of sociability or contexts: family, friends, neighbourhood, leisure or educational activities, religious practice and workplace.

Section 3 / 1 - 4	To identify the health information and advice networks of participants, I used an exchange approach adapted from the ‘name generator’ used in the General Social Survey (GSS) in the US: <i>Who are the people with whom you discussed matters important to you?</i> ” (Marsden 1987), but I focused the ‘important matters’ on SRH matters (e.g. STIs, cervical screening, HPV self-sampling).
Section 4 / 1 - 8	To describe the composition of participants’ social networks, I used age, sex, education level, relationship type, country of origin and place of residence as variables. With this information, I sought to identify any homophilic patterns, for instance, by calculating the proportion of Spanish ties and transnational contacts in the participants’ networks. I also added questions to describe the social interactions between the ‘ego’ and ‘alters’, including frequency of contact and communication channel.
Section 5 / 1 - 2	To explore the potential influence of subjective norms, I included a specific injunctive norm-related question, which asked participants whether someone in their family had ever recommended them to get screened for cervical cancer.
Section 6 / 1	To explore the potential influence of subjective norms. In this case, I included a descriptive norm-related question, seeking to capture the perception of participants about the prevalence of female contacts who had ever got screened for cervical cancer.
Section 7 / 1-2	To examine the strength of the relationship between the ‘ego’ and ‘alters’ (e.g. close vs weak ties), and the links between participants’ contacts in order to measure the density of the networks. I used a sociogram to capture these two network elements (strength and connectedness).

B. HPV-self-sampling Acceptability Survey

All participants completed a socio-demographic questionnaire (see Appendix 9), including standard questions (e.g. age, marital status, number of children, religion), as well as questions related to access of healthcare services, screening status and self-efficacy about HPV self-sampling.

Towards the end of the FGDs and SSIs, women were shown two self-sampling devices, as explained above, and they were invited to try them at home. The decision to use these devices was because both

have been validated for HPV detection on multiple PCR-based HPV assays (Hawkes et al., 2020). More specifically, the decision to use FloqSwab was informed by its successful implementation in ongoing pilot studies in Catalonia (Robles and Peremiquel, 2023; Peremiquel et al., 2022) and the inclusion of EvalynBrush was based on its prior use in studies conducted previously in Spain (Ibañez et al., 2023).

Those women who agreed to try the self-collection devices were asked to complete a paper self-administered questionnaire to assess the acceptability of the HPV self-sampling devices (see the tool in Appendix 10). The questionnaire was adapted from a previous tool designed by ICO and based on a literature review of other questionnaires and tested locally for clarity and cultural fit prior to implementation of a randomized clinical trial among women attending CC screening in Catalonia and Canary islands (Ibañez et al., 2023). The socio-demographic and acceptability questionnaires were translated into four languages: Arabic, Urdu, English and Spanish, and were assessed for comprehensiveness by bilingual community health providers who were part of the fieldwork team, as well as external language ‘experts’ (a Moroccan medical student at the University of Barcelona and a Pakistani Public Health doctoral student from LSHTM).

The questionnaire used for my study with Moroccan and Pakistani immigrant women included 19 items to assess their screening preferences (self-sampling over clinician-collection); their perceived self-efficacy (whether participants thought the sample was collected properly); the ease to use the device and its safety; if they felt pain; how long it took to collect the sample; if they needed assistance to understand the instructions and/or to collect the sample; their trust in the test result from the self-collected sample; their willingness to use self-sampling again in the future; where they would like to collect and return the self-sample device and whether they would recommend to use it to family and friends. Primary and secondary outcome measures are described in section 4.5.3 Quantitative data analysis.

Women who declined the invitation to try the self-collection devices and women who took the devices home but did not return the acceptability questionnaire were asked to fill a ‘non-acceptability’ questionnaire (see Appendix 10) in which they were asked about the reasons for not participating in the trial or not returning the acceptability questionnaire. Different responses, including not having time, no interest in the study, fear of harming themselves, low self-efficacy and difficulties to understand the instructions, were given to the participants who were able to add other reasons.

The two RAs were responsible for following up on the completion of the questionnaires and providing help to participants when needed. The quality of quantitative data was ensured through a systematic revision of each questionnaire by me and two researchers from ICO. If data was missing or confusing,

we contacted participants by phone or through the fieldwork team members to complete the questionnaires, when possible. Researchers from ICO and I were responsible for entering the data in RedCap (Harris et al., 2009; Harris et al., 2019), which was held by ICO.

4.5 Data analysis

4.5.1 Thematic content analysis

All FGDs and SSIs conducted in the participants' local languages (Arabic/Darija and Urdu) and Spanish were audio recorded. Due to the oral nature of women's local languages (e.g. Darija) and the resource and time constraints, we decided to transcribe the audio recordings from Arabic/Darija and Urdu directly into Spanish and English, respectively. This limitation was mitigated by the fact that the two RAs were fluent in the participants' languages and Spanish and English. Furthermore, both RAs applied a 'conceptual equivalence' approach in the translation and transcription of the participants' accounts, which is preferred for qualitative research, since it is a method that translates participants' ideas rather than their words (Cormier, 2018). I transcribed in the same way all my interviews conducted in Spanish with participants from both countries and some of the interviews conducted with healthcare providers (part of the interviews with providers were transcribed by a Colombian physician and Master student in Public Health in Barcelona, who was part of the ICO team).

To ensure rigour, I carefully revised all transcripts and compared the contents with the notes I took during the debriefing sessions after each FGD and SSI with the two moderators and RAs. In fact, the analysis and interpretation of the results started in these preliminary debriefing sessions, where we discussed emerging themes, clarified participants' quotes and agreed on interpretation of specific accounts. This quality-check process continued after revising all transcripts by frequent consultation with the RAs about those excerpts which I could not fully understand due to cultural differences or literal translation instead of 'conceptual equivalence' translation. When a participant's quote from a FGD seemed incomplete or subject to a double interpretation, I involved other multi-lingual team members to assist with the interpretation by listening the audio recording and providing their translation. Once I had the final transcriptions, I conducted the coding in English and for the analysis and interpretation I combined Spanish and English as the transcriptions were in these two languages.

Conventional content analysis (Hsieh and Shannon, 2005) or data-driven analysis was the analytical approach adopted to start the data coding. As the open coding progressed, I also applied a deductive analytical approach (researcher/theory-driven) using constructs from behavioural theories (e.g. risk perception, perceived self-efficacy, subjective norms) and specific themes found in previous literature

(e.g. healthcare accessibility barriers). This hybrid approach (Fereday and Muir-Cochrane, 2006) allowed me to develop a comprehensive codebook to facilitate analysis.

I followed the six steps proposed by Braun and Clarke (2006) to conduct a thematic content analysis with some changes in the order. Another researcher from ICO and I familiarised ourselves with the data and conducted the initial open coding phase independently guided by an inductive approach, as mentioned above. This open coding was carried out manually using pen-and-paper and Microsoft Word (see illustrative excerpt of data analysis in Appendix 11). We first identified broader themes (e.g. cancer, self-care and prevention; CC screening; HPV self-sampling implementation) and after this, we developed sub-themes and codes, combining descriptive (e.g. 'informed screening choices'), in vivo (e.g. 'when having symptoms'; 'God's will') and values codes (e.g. 'HPV self-sampling attitudes') through an iterative process. After discussion, we reached an agreement on an initial codebook and I developed the final codebook with the help of the qualitative data management software ATLAS.ti 23 incorporating new emerging codes or removing those which were not relevant. To validate the themes and codes, the above researcher from ICO coded additional transcripts using the final codebook and I refined those codes that were still unclear in ATLAS.ti. I applied the codebook to all participants' transcripts and the analysis was conducted by country of origin in order to be able to compare findings from Moroccan and Pakistani participants. I developed another codebook for the healthcare providers' transcripts following the above steps.

The proposed SEM (see Chapter 3) helped me to organise and conduct a multi-level analysis of the themes and codes (individual, interpersonal, health system levels). Although thematic content analysis was the primary approach, I also applied discursive analysis (Cheek, 2004) to identify emerging themes related to religious beliefs. For example, I found relevant the constant presence of God in women's discourses.

4.5.2 Social network analysis

In my egocentric social network analysis, I used descriptive statistics to summarize the socio-demographic characteristics and screening status of the 22 'egos' (12 participants from Morocco and 10 from Pakistan) by country of origin. Summary statistics were also used to elicit the composition of the participants' personal networks, including the characteristics of the 'alters' (women's contacts): gender, age, education level, country of origin, country of residence, relationship of contact to respondent, frequency of contact and channel of communication (see Tables 12 and 13 in Chapter 6). This was performed in STATA (StataCorp, 2019) and it allowed me to explore, for example, the proportion of immigrant contacts, family members or Spanish friends in these immigrant women's social networks. I also calculated in R (R Core Team, 2021) the proportion of possible ties between 'alters' that were in fact present in each social network (density), which may be relevant in terms of

health information transmission. For instance, in dense networks composed predominantly of family members (strong ties) health information support may be more limited than in diverse networks that include weak ties, such as co-workers, who may provide new information not available in close circles.

Since the ultimate objective of this thesis was to explore effective ways to improve CC screening among these two immigrant populations, I also focused the analysis on the potential normative influences on women's screening behaviours, by calculating the proportion of alters who: 1) according to participants' perceptions had ever undertaken a Pap smear; 2) had ever recommended them to get screened for CC and 3) thought that the participant should undertake a Pap smear (see Table 14 in Chapter 6). Due to the small sample size, I was not able to calculate the effect of women's social networks' characteristics (e.g. size, presence of Spanish friends) on their screening behaviours, however, this thesis provides the basis for future survey research addressing the role of networks on CC screening behaviour and other health behaviours.

For my egocentric network analysis, I also used the visualization of participants' personal networks, which were created in the statistical software R (R Core Team, 2021) using igraph package (Csárdi et al., 2024; Csárdi and Nepusz, 2006). The network graphs (see Figure 5 and Appendix 8) helped me to better understand the composition of the networks and they also allowed me to identify patterns and typologies of networks, for example, with clusters of Spanish contacts, more family-oriented, dense vs fragmented networks, and compare them. Due to time constraints, the analysis of the network graphs focuses only on gender and ethnic homophylic patterns, however, the network graphs of the 22 participants were built and are available for future analysis, for instance, on the association between types of networks or specific network features (presence of Spanish contact clusters) and screening status.

4.5.3 Quantitative analysis of survey data

Quantitative data from the socio-demographic and HPV self-sampling acceptability questionnaires were encrypted anonymously using Research Electronic Data Capture (REDCap) and hosted at ICO (Harris et al., 2009; Harris et al., 2019). We then processed the datasets in STATA, labelling and grouping data appropriately. We used descriptive statistics (frequencies, percentages and means) in the same software to describe the socio-demographic characteristics and self-reported screening status of participants from Morocco and Pakistan.

Due to the small sample size, the study to assess acceptability of HPV self-sampling was not powered to make statistical inferences and no statistical hypothesis testing was pre-planned. Therefore, I conducted a simple descriptive analysis explained below:

The primary outcomes for this study were a) the proportion of women who accepted to try at least one of the two devices at home and return the acceptability questionnaire and b) the proportion of women with preference for home-based self-sampling over clinician-based screening. As secondary outcomes, we measured different individual aspects of the self-sampling experiences, such as their perceived self-efficacy (whether participants thought the sample was collected properly); ease to use the device and its safety; if they needed assistance to understand the instructions and/or to collect the sample; how much they trust in the test results and willingness to use self-sampling again in the future. The responses were reported as percentage of the different gradients (e.g. from “Yes, I’m sure” to “I’m not sure I picked it up right”; from “I found it very easy” to “It was very difficult”) and of dichotomised variables (i.e., “Yes” and “No”).

I first planned to calculate the overall proportion of participants who accepted to try the HPV self-sampling devices, by country of origin and, but also by other variables, such as age, employment status, time since migration, screening status (Table 18). I then planned to conduct an ad-hoc analysis using Fishers Exact Test or Pearson’s Chi-Squared Test (as appropriate) to compare the acceptance rates between the following groups: Moroccan and Pakistani women, previous screening, employed and unemployed, and time since immigration. However, these results should be interpreted with caution due to the small sample size.

I also used descriptive statistics to report women’s screening preferences, confidence in using the devices properly (perceived self-efficacy), their trust in the test results, their willingness to use it again and recommend it to family and friends. Women were also asked about their experience using the devices and to rank different categories (i.e., privacy, safety, normality, calm, comfort) in a scale from 0 (“none”) to 10 (“a lot”) (Table 20 and Figure 6). All these outcomes were presented by type of device, not with the purpose of making comparisons between devices, but only to describe women’s experiences using each device.

Regarding missing data, the two RAs and I ensured that participants provided a response to each question. However, a small amount of missing data was reported which was excluded from the calculations. Using the non-acceptability questionnaires I also compared the reasons reported by participants with the ones reported during the qualitative FGDs and SSIs.

4.5.4 Triangulation of data

The process of combining findings or triangulation can be used to describe corroboration between two sets of findings (from different sources) or to describe a process of studying a problem using different methods to gain a more complete picture (O’Cathain, Murphy and Nicholl, 2010). As I explained previously, in this qualitative-driven mixed-method study, the process of triangulation (of data sources and methods) occurred at different points, but concerning the analysis and interpretation of the findings, I combined a ‘convergence’ and ‘complementarity’ triangulation approaches (O’Cathain, Murphy and Nicholl, 2010). For instance, I looked for (dis)agreements between the findings from the FGDs and SSIs, and the findings from the HPV self-sampling acceptability survey, but also found that both datasets complemented each other. For instance, the quantitative data validated the preference of Moroccan and Pakistani women for clinician-based screening over self-sampling reported in the qualitative data (convergence), and qualitative data provided the potential explanation for this preference (complementarity). I also triangulated data from immigrant patients and healthcare providers, searching both for dissonances and complementarity of data from different perspectives. For instance, I found inconsistencies in immigrants’ and healthcare professionals’ narratives regarding the use of primary care services. Whereas some healthcare providers reported inadequate use or overuse of primary care services by immigrant populations, women’s narratives indicate a tendency of using emergency services rather than primary care. Both views were presented in the results of this thesis and I undertook a literature search on this topic to help me with the interpretation of these findings.

4.6 Reflexivity

Acknowledging our own social position (gender, age, race, migration status), beliefs, bias and judgement systems is a critical part of any research process, as these may have an effect on the setting and people being studied, questions being asked, data being collected and its interpretation (Lazard and McAvoy, 2020; Berger, 2015). As Charmaz (2006) argues, the researcher is not a ‘neutral observer’, but a ‘co-participant’ in the study and as such, I engaged in self-reflection during the research process to critically acknowledge my position and question my own preconceptions. My past and present migration experiences, my insights from the SRH projects I have been involved in and my personal convictions about social justice, with particular attention to women’s and migrants’ health rights, have imbued this research.

First, I engaged in reflexivity evaluating my familiarity with and beliefs about the participants’ culture and their social and religious values and questioning my own cultural competence to conduct this research. My first contact with the Moroccan and Pakistani cultures was through my travels to

Morocco and friendship with Pakistani immigrants in Scotland, and my vague knowledge about Islam came primarily from male Muslim friends in Spain, as well as my readings and travel experiences in predominantly Islamic countries (e.g. Morocco, Iran, Palestine, Egypt, Turkey). Despite having some insights into the participants' culture and religion, I made great efforts to put aside my assumptions, for instance, regarding the role of the women in Muslim societies, and I adopted a 'fresh' and open position to learn from the female team members with a Moroccan and Pakistani background and the participants' accounts to explore the intersectionality across religion, gender and migration. Most of my interviews with Pakistani women were conducted in the mosque, where I always respected the dress codes, and I adopted an open attitude to interacting with members of the community to learn as much as possible about their beliefs, values and life-style. In the case of Moroccan women, most of my interviews were conducted in the participants' homes, which also gave me the opportunity to obtain information about their life-style, traditions and cultural values.

Second, reflexivity also involves to move away from one's own culture (Lather, 2017), in my case 'Western' (Spanish) culture and a Christian agnostic position. To avoid bias, the literature review informed my interview topic guides and survey questionnaires, but I also incorporated the inputs of key informants from the Moroccan and Pakistani communities. Moreover, I tried hard to adopt a non-judgmental approach during my interviews with the participants, a skill I personally felt I developed during my previous career as a journalist. For the interpretation of the findings, I sought validation from the RAs and other members in the team to elude potential bias. Despite all these efforts, during the writing up of my research papers, I still identified unintentional bias, for example, in specific expressions, like "passive" self-care and prevention attitudes, referring to participants' lack of habit of doing regular check-ups, instead of using terms such as "unfamiliar" with 'Western' concepts of self-care and prevention.

Third, I played two roles in this project, both susceptible to tensions, which in turn might have affected the research process and outcomes. First, I was the budget-holder for the data collection phase and, thus, responsible for paying the RAs, FGDs' moderators and translators, as well as covering any fieldwork expenses (e.g. compensation of participants for taking part in the study, logistics of the FGDs). This put me in a position of relative power in terms of decision-making, but I made every effort to avoid a top-down approach. Since I was aware that the budget was limited, I adopted a transparent and informative approach. Prior to data collection, I held individual and group meetings with the fieldwork team members to provide details about the budget and the nature of the work (e.g. training, number of hours required, tasks). Since all the team members, including the translators, had their own jobs and study responsibilities, I tried hard to be flexible and accommodate their needs without altering the fieldwork timeline too much, which was challenging and not without tension. For example, I had to adjust the work plan several occasions, as the Moroccan RA had to

complete university assignments and the Pakistani RA got married at the end of the data collection process. Second, I also played a dual fieldwork leader and PhD student roles. I led the participant recruitment process, training of the fieldwork team and the coordination of the interviews and focus groups, with the support of the team leader of the Community Health Unit of Drassanes (Vall d'Hebron hospital, Barcelona). This also generated some power imbalance, which created tensions at some points. For instance, the RAs were at times confused about to whom be accountable and clarification of roles was needed in several occasions.

Fourth, my position as an 'outsider' during data collection might also have had an effect on the research. Despite being introduced to the fieldwork team by Catalan researchers (ICO), I felt myself as an 'outsider', first, because I was a Spanish PhD student but from a foreign academic institution (LSHTM) and I did not speak Catalan, and second, because of my position as a white Spanish-born person working with Moroccan and Pakistani immigrants in Spain. I spent a lot of time reflecting on how to promote ownership of 'my PhD project' and how to build trust between me and the fieldwork team members, all of whom were immigrants from Morocco and Pakistan, except for the researchers from ICO. This was a crucial reflexive part of my data collection phase as I was aware of my dependency on the fieldwork team when recruiting and meeting with participants due to my language limitations (I do not speak Urdu nor Arabic/Darija) and my lack of contacts in these communities and among healthcare providers in Barcelona. My dependency on them was also evident to get contextual information (e.g. characteristics of these two specific immigrant groups in Catalonia).

Building trust was initially challenging. I strived to do my best to build trust gradually with the fieldwork team. For instance, by giving details about my professional background, sharing my own migration experiences in the UK with them and, most importantly, recognising my knowledge gaps about Moroccan and Pakistani cultures and also emphasizing the important role of the fieldwork team in the study as 'cultural brokers'. Despite all my efforts, there were some tensions especially with the Pakistani team members. For instance, they were initially resistant to ask the participants questions related to the role of the Islam in women's self-care and prevention attitudes and practices. I overcame these mistrust issues by carefully explaining the rationale of the questions and providing them with examples. Prior to data collection, I was aware of the presence of Islamophobia in Spain and I made every effort to avoid any misunderstanding in this direction.

Although the FGDs were conducted in the participants' local languages and moderated by two experienced community health professionals from Morocco and Pakistan, my presence as an 'outsider' could have had an impact on the data. I tried to keep myself as discreet as possible, maintaining short conversations in English and Spanish with the participants, when possible. On the contrary, my relationship with the Moroccan and Pakistani women who were interviewed in Spanish

became much closer as recruitment of new participants and data collection progressed. For instance, my presence in the mosque was more familiar after a few visits for meetings and interviews with Pakistani women. I would not say my position was that of an ‘insider’, but people recognised and welcomed me, suggesting some sort of trust. Similarly, my interviews in the Moroccan participants’ homes offered a more intimate space, where I had the opportunity to build some kind of complicity with them and a more nuanced understanding of their daily lives in Spain apart from their views on the subject under study, as explained above. I feel my position as an immigrant in another country (United Kingdom) also helped me to build rapport with the participants, by sharing similar issues or anecdotes regarding our interactions with the health systems in each country (Spain and UK). My migration experiences also gave me an ‘insider’ perspective when analysing the data and helped me to comprehend better specific health care accessibility issues.

Finally, I assumed that my position as a single professional woman without children could be interpreted or categorized within ‘Western’ social and cultural values by participants and generate some rejection or distance between us. This assumption was based in past research experiences with women in Ethiopia and El Salvador, where the reproductive role of a woman is highly valued. However, my experience with the Moroccan and Pakistani women who spoke in Spanish was much more inclusive.

4.7 Ethical considerations

The study was approved by the Research Ethics Committees of the London School of Hygiene and Tropical Medicine (LSHTM Ethics Ref: 26186) in the United Kingdom, and Bellvitge University Hospital (PR 140/22) and Vall d’Hebron University Hospital (PR(AG)317/2022) in Catalonia, Spain. Approval letters are added to Appendix 13. The study adhered to the principles outlined in the Declaration of Helsinki, the LSHTM Standard Operational Procedures (SOPs) and the ICO SOPs, and any other regulatory requirements, such as the Organic Law 3/2018 of December 5 and Regulation (EU) 2016/679 of the European Parliament and of the Council, of April 27, 2016, regarding the protection of physical persons in relation to the treatment of personal data and the free circulation of these data (“General Data Protection Regulation” or “RGPD”), in full application since May 25, 2018, as well as any other regulations based on these laws (UK RGPD) (see Ethic Committees’ approval letters in Appendix 14).

4.7.1 Informed consent

Written consent was obtained from all participants prior to each focus group and individual interview and after providing the required information about the study. To ensure that all participants made an

informed decision about their participation in the study, they were informed of the purpose and nature of the study through both an oral explanation and an information sheet. The information sheet and the consent form (see Appendix 12) were available in four languages: the participants' local languages (Arabic/Darija and Urdu), as well as Spanish and English. Prior to the FGDs and the SSIs, the moderators and RAs summarized in Arabic/Darija and Urdu the topics they would be discussing - providing them with some sample questions - along with the structure and time of the sessions. They also explained to participants how the information they would provide would be used and asked them for permission to audio record the sessions. Participants were then given time to read the information sheet and ask any questions before the FGDs and SSIs began.

4.7.2 Conducting research with vulnerable populations

Vulnerability in research occurs when the participant is unable to protect her/his interests and, therefore, has higher probability of being harmed. The vulnerability can be due either to an inability to understand and give informed consent or to unequal power relationships that hinder basic rights. Excluding participants from research for the sole reason of belonging to a vulnerable group is unethical and would bias the study findings (González-Duarte et al., 2019). I selected the study sample taking this into consideration and participants of all education levels, including illiterate women, were recruited. Nine out of the seventy-three women who participated in the research reported not having attended school and of these, three were illiterate. This presented some ethical concerns when obtaining informed consent from these participants and during the FGDs or SSIs to understand the questions and/or the activities proposed. Great care was taken to minimise the risk of harm to these participants. A literate adult witness (e.g. a family member or a multi-lingual team member) was present to read the information sheet and the informed consent form prior to the FGDs or SSIs. Furthermore, the RAs provided additional support to these participants during data collection, for instance, in completing the socio-demographic questionnaire (in person) and the acceptability questionnaires (by phone and/or in person), and by providing explanations in simple language, when needed.

4.7.3 Risks to participants

CC may be a stigmatized disease in some cultural contexts and it is a highly sensitive topic. Therefore, sharing views, perceptions and experiences of cancer within their family, friends and community circles may cause discomfort and distress to participants. Furthermore, the fact that the disease is caused by the HPV, a common sexually transmitted virus, may cause women discomfort as they can consider taboo talking about testing for a STI or disclose a positive HPV result.

We ensured that participants were not disturbed by talking about cancer or other personal health issues, ensuring their privacy and building rapport with them with the help of the FGD moderators and the RAs, who had the same cultural and linguistic background as participants and were well-known in these communities. It was also important to recruit female RAs, as the participants felt more comfortable talking about their personal experiences and speaking about women's health with a female peer. During the informed consent process, each participant was told they could discontinue their participation in the research at any time and that they did not have to answer any questions which made them feel uncomfortable; this message was repeated at the beginning of each FGD and SSI and at any difficult or emotional moments during the sessions. On the other hand, the interview topic guides were carefully elaborated and appropriate language was used.

As explained previously, all participants were invited to try two different HPV self-sampling devices. To avoid any feelings of pressure or coercion and to ensure that women made an informed decision, they were informed in advance that they did not have to use the self-sample devices, if they did not want to, and if they decided to use the devices, they also were informed orally and written in the information sheet that the collected sample was not going to be processed in the laboratory, thus the sample result would not be available. Alternatively, women were invited to undergo CC screening in their primary healthcare (PHC) centre and they were offered assistance from the fieldwork team members to arrange the screening appointment or provide further information and refer to the corresponding services.

Social network data collection can be particularly burdensome for researchers and participants, affecting the quality of data, but also increasing the risk of discomfort among participants. To mitigate this risk, the SNA protocol was carefully elaborated and piloted to not last more than an hour, and the participants were informed that the interviews could be split over two days, if necessary. Finally, all FGDs and SSIs were conducted in a convenient place, easy to access for the participants and in strict privacy, and we respected the available times of participants, in order to avoid any disruption to their daily routines.

4.7.4 Benefits to participants

The information gathered in this study will contribute to adaptations of the newly introduced organised CC screening program which is being implemented in Catalonia, Spain, and/or the design of culturally tailored interventions to improve the screening uptake among these two immigrant populations in this region and beyond. Through their participation in the study, participants gained accurate information about the disease and its causes, and the screening options available, being empowered in their health decision-making processes, but also in supporting and transmitting

information to other immigrant peers about the importance of screening. This is also an opportunity to engage immigrant women in cancer prevention interventions and, what is more important, to make sure their voices, views and recommendations are heard and taken into account in the implementation of screening programmes.

4.7.5 Confidentiality and protection of data

To ensure confidentiality of the research data obtained from the participants and key informants (healthcare providers), the research team, including researchers, RAs and translators, and all participants in the FGDs signed a confidentiality agreement (see Appendix 13) prior to beginning the fieldwork activities. Additionally, we used unique identifiers rather than full names for field notes, focus groups and interview transcripts and audio recordings, as well as for the analysis and dissemination of findings. When processing the quantitative data and performing descriptive statistics, we grouped the variables carefully to avoid any potential identification of participants, as some values were too small. Regarding the health providers, we omitted the identification of the health centres where they worked and other personal information. Any identifiable personal information was stored only on password-protected, encrypted devices or in locked spaces. Information was securely kept at the servers of the collaborating institutions (LSHTM and ICO) and only collaborators granted permission to access data.

4.7.6 Compensation for participation

All participants received a small incentive (a public transportation 10-trip pass) after each of the FGDs and SSIs as a compensation for the transport cost and time given to the research. In order to avoid undue influence due to excessive rewards, I consulted with the team members in Barcelona and the proposed incentive was considered appropriate for this population and context.

Chapter 5: Exploring self-care and cervical cancer prevention attitudes and practices among Moroccan and Pakistani immigrant women in Catalonia, Spain: a comparative qualitative study

5.1 Introduction

This chapter provides an introductory reflection on the applicability of the concepts of self-care and health prevention in the implementation of public health interventions targeting populations with different cultural and religious backgrounds. By using the case of the CC screening programme in Catalonia, Spain, this chapter explores health beliefs and self-care and prevention attitudes and practices of Moroccan and Pakistani immigrant women. The data analysed in this chapter establish the grounds for this PhD study by exploring the participants' health belief systems and how these may influence women's health priorities and self-care practices, as well as healthcare-seeking behaviours, in this case, the use or not of CC screening services. Therefore, the findings presented here address individual determinants of health prevention behaviours corresponding to the first research objective of this thesis: to explore perceptions and beliefs about CC screening among Moroccan and Pakistani immigrant women. Other individual determinants, such as knowledge and risk perception are addressed in Chapter 8, which is focused specifically on HPV-based screening.

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	LSH2004190	Title	Ms
First Name(s)	Jone		
Surname/Family Name	Garcia Lurgain		
Thesis Title	An ecological exploration of the barriers and facilitators to cervical cancer screening and HPV self-sampling acceptability among Moroccan and Pakistani women in Spain		
Primary Supervisor	Joanna Busza		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	BMC Public Health		
When was the work published?	6 February 2024		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	n/a		
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	

Stage of publication	Choose an item.
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SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I am the first author of this paper and I was responsible for study design and data collection, and I led on the analysis (with support from my supervisor Joanna Busza) and interpretation of the data. I was also responsible of the conception of the paper and wrote the first draft of the manuscript, received feedback from all co-authors and responded. I led on the manuscript submission to the journal, and was responsible for responding to all reviewer comments and resubmission of the paper.</p> <p>This manuscript was published with creative common licence CC-BY</p>
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SECTION E

Student Signature	Jone G Lurgain
Date	24 June 2024

Supervisor Signature	Joanna Busza
Date	24 June 2024

5.2. Abstract

Background: Self-care and preventive health strategies may trigger health inequities when individuals' cultural values and health beliefs are not fully understood and considered. In the case of cervical cancer (CC) screening programmes immigrant women have shown lower attendance compared with native women, which increases the risk of late diagnosis and, consequently, a lower probability of survival. HPV self-sampling for CC screening has been recently added to the World Health Organization's (WHO) list of self-care interventions as a promising tool to reduce this disparity and improve screening coverage. In Catalonia, Spain, the introduction of HPV self-sampling as a part of the new population-based CC screening program, is a significant step. However, there is a lack of research addressing self-care and prevention among immigrant populations in this region. This study aims to fill this gap exploring self-care and prevention attitudes and practices among Moroccan and Pakistani women.

Methods: We conducted focus groups and individual interviews with 36 Moroccan and 37 Pakistani women in Barcelona, Spain. The topic guide of the focus groups included case vignettes to stimulate the discussion and a semi-structured questionnaire was used for the interviews.

Results: Our findings show that most Moroccan and Pakistani women do not prioritize self-care and prevention. They seek care for symptom treatment rather than disease prevention. In this sense, they reported not having the habit of doing regular check-ups and their self-care and prevention attitudes and practices seemed to be conditioned by cultural values. The implementation of an effective call and recall system could enhance the engagement of these populations with CC screening services.

Conclusion: This study provides evidence on how universal concepts of self-care and prevention may not be aligned with more collectivist societies, emphasizing the limited applicability and motivation of global self-care intervention guidelines for individuals with different cultural backgrounds and values. Therefore, the successful implementation of CC screening programmes or any other self-care intervention requires the adoption of culturally appropriate strategies.

5.3 Research paper 1

Background

Self-care and preventive health strategies empower individuals to take an active role in managing and assuming responsibility for their own health. However, this well-intentioned approach may inadvertently exacerbate health inequities when individuals' cultural values, beliefs and health priorities are not well understood, and enabling environments are lacking. Cervical cancer (CC) screening programmes exemplify preventive care practices that inadvertently contributes to health disparities. Immigrant women have lower CC screening attendance compared with native women across different European countries, including Spain, which in worst case can result in higher incidence rates, later diagnosis and treatment and, ultimately, a lower probability of survival (Rosato et al., 2023; Marques et al., 2023; Tatari et al., 2020). Also, a higher prevalence of abnormal screening results among immigrant women compared to native counterparts, reveals the importance of prioritizing CC screening in these populations (Rodriguez-Sales et al., 2013). The World Health Organization (WHO) has recently added HPV self-sampling for CC screening to its list of self-care interventions as a promising tool to reduce this disparity and improve screening coverage (WHO 2022). The impact of the COVID-19 pandemic on healthcare systems, exacerbating the existing challenges and constraints they face, and an increasing prevalence of chronic diseases worldwide have contributed to this new global self-care approach to preventive care, which traditionally relied on health professionals (Narasimhan, Aujla and Van Lerberghe, 2022; Martinez et al., 2021; Asmez and Llorente, 2023). However, in increasingly multicultural societies it is crucial to adopt a more inclusive perspective to address self-care and preventive health concepts - often viewed from a 'Western' perspective - to implement effective health promotion interventions.

Self-care is a dynamic and multidimensional concept that has evolved over time (Wilkinson and Whitehead, 2009; McCormack, 2003; Kickbusch, 1989). For instance, different practices, such as cultural rituals, consumption of special foods to promote health and the intergenerational sharing of knowledge are examples of self-care strategies. However, it was not until the late 20th century that the ability to provide care for oneself gained recognition in the global health arena and started to be applied to the management of chronic diseases (Martinez et al., 2021). Global health organisations now use a more holistic concept of self-care that encompasses individual and collective actions taken not only by people with an existing health problem to self-manage their illness, but also by healthy people to prevent disease and maintain health. The WHO latest definition of self-care is “*the ability of individuals, families and communities to promote health, prevent disease, maintain health and to cope with illness and disability with or without the support of a healthcare provider*” (WHO, 2013).

As the concept of self-care continues to evolve, numerous frameworks have emerged to guide the assessment of individuals' engagement with self-care practices. For example, the International Self-Care Foundation (2018) proposes seven domains of self-care: health literacy and health seeking behaviour; self-awareness of physical and mental health (e.g., engaging in health screening, monitoring blood pressure); adopting healthy eating; performing regular physical activity; risk avoidance (e.g. limiting alcohol consumption, getting vaccinated or practising safe sex); maintaining good hygiene; and ensuring a rational and responsible use of medicines.

The Catalan health system is aligned with the above WHO's self-care and prevention approach and has targeted programmes and resources on promoting a healthy diet, physical activity, mental health, vaccinations and screening (GENCAT/Salut, 2021a, 2021b). However, despite the availability of these services, very few studies in Catalonia, Spain, have addressed immigrant women's perceptions, beliefs and practices about self-care and preventive care. These 'Western' models of self-care may not adequately apply to understandings of self-care among immigrants. Healthcare providers and policy makers must understand diverse cultural health beliefs in order to tailor health promotion interventions, including CC screening, to the needs of these groups and thus guarantee their access to quality preventive care. Therefore, the objectives of this study are to examine immigrant (Pakistani and Moroccan) women's perceptions and beliefs related to health and illness, to explore their understanding of self-care and attitudes towards disease prevention, and to assess how these perceptions and health beliefs may influence self-care and prevention practices, especially CC screening.

Methods

Setting and study population

This study is embedded in a broader CC screening implementation study in Catalonia, Spain, where the CC screening programme is transitioning from opportunistic to population-based strategy and HPV self-sampling has been introduced as sampling method. Moroccan and Pakistani immigrant women represent the 3 % (104,382) and 0.72 % (17,416), respectively, of the total female immigrant population in Barcelona province (IDESCAT 2022a). Both communities share the same religion, as well as certain social norms in their respective patriarchal societies. However, they have different cultural, linguistic and migration histories - although in both groups many of them came to Catalonia through family reunification policies. Moroccan immigrants have a longer history of migration to Spain compared to Pakistani immigrants. The geographical closeness between Morocco and Spain and the international migration agreements between these two countries contributed to early waves of

Moroccan immigrants - currently one of the largest immigrant communities in Spain -, whereas Pakistan and Spain never had strong cultural and social bonds, nor economic agreements making the Pakistani migration history to Spain a more recent and distinct case (Ayala and Dalouh 2014; Kosmynka 2020).

Sample and participant recruitment

The study population consisted of 73 immigrant women born in Morocco and Pakistan, who migrated to Catalonia at 16 years old or older (thus not exposed to the Spanish public education system) and have lived in Catalonia for at least one year. Inclusion criteria for selecting the sample were the same as those used by the CC screening program in Catalonia: women aged 25 or that will turn 25 in the year of the study, to 65 who have never been diagnosed with this cancer. Participants were recruited in neighbourhoods of different municipalities: Raval (Barcelona city), La Mina (Sant Adrià del Besòs), Ca n'Anglada (Terrassa) and Torrassa (L'Hospitalet de Llobregat). All are socially deprived areas with high concentration of immigrants in the province of Barcelona (IDESCAT 2022b). Convenience and purposive snowball sampling (Given, 2008) were combined, based on the age, education background and length of stay in Spain. Recruitment was done through the networks of the community-based Research Assistants (RAs) from Morocco and Pakistan who were bilingual in Spanish or English and Urdu or Darija (participants' native language) and were university students in Psychology and members of the Community and Public Health team of the Drassanes - Vall d'Hebron Centre for International Health and Infectious Diseases, in Barcelona. The RAs connected with religious and community associations and non-governmental organisations, in addition to referring acquaintances.

Data collection

Data were collected between September and December 2022 through eight focus group discussions (FGDs) and twenty-two semi-structured interviews (SSIs). Table 9 provides a detailed breakdown of the participation and languages used. FGD and SSI guides were informed by previous literature and adjusted to explore emerging topics and clarifying questions that respondents found difficult as data collection progressed. All FGDs and SSIs were audio-recorded and transcribed verbatim directly from Darija and Urdu into Spanish and English, respectively. The RAs as well as the rest of the personnel implicated in the study were trained in ethical procedures and HPV and CC screening basic knowledge.

Table 9 Breakdown of participation and languages used.

Methodology	Number of participants	Language
<i>Moroccan participants (n=36)</i>		
Focus Group 0	3	
Focus Group 1	7	
Focus Group 2	4-6*	Arabic (Darija)
Focus Group 3	8	
Semi-structured interview	7	
Semi-structured interview	5	Spanish
<i>Pakistani participants (n=37)</i>		
Focus Group 0	3	
Focus Group 1	9	
Focus Group 2	7	Urdu
Focus Group 3	8	
Semi-structured interview	5	
Semi-structured interview	1	Punjabi
Semi-structured interview	4	Spanish
Total	73	

*Two participants had to leave the focus group earlier as they had personal appointments

All participants completed a self-administered questionnaire available in four languages (Spanish, English, Arabic and Urdu), capturing socio-demographic information, as well as Spanish language proficiency, religion identification, employment status and CC screening experience. A total of 24 Moroccan women and 27 Pakistani women participated in one of the eight FGDs, which were moderated by two experienced community health providers (a nurse and community health agent) who shared language and cultural background with participants. All FGDs were conducted in Urdu or Darija, which were the native languages of Pakistani and Moroccan women, respectively. The FGDs were organised by the community-based RAs through face-to-face contact and by phone and were facilitated in convenient and familiar places for the participants, such as community centres, faith-based associations and health facilities. Each group included between three and nine women and lasted around 2 hours. The topic guide included case vignettes to stimulate the discussion. Women were presented with the fictional case of Fatima, an immigrant woman diagnosed with CC, and were asked two questions related to her self-care and prevention attitudes and practices:

1 Fatima was diagnosed with cervical cancer. What do you think she could have done to prevent cervical cancer?

2 Since her last son was born eight years ago, Fatima did not visit the gynaecologist to do a check-up. Why do you think she did not go back to the gynaecologist and she did not undertake a Pap smear?

The SSIs (12 with Moroccan women and 10 with Pakistani women) were conducted by the RAs and the principal investigator (PI). The RAs were specifically trained in interview techniques and topic guides prior to the interviews. The SSI length ranged from 35 to 75 minutes and were carried out in a place of convenience selected by participants (e.g., their homes, interviewers' home, health facilities and religious centres). The SSIs followed a semi-structured topic guide, which included topics such as participants' perception of self-care, self-care and prevention attitudes and practices and motivations towards disease prevention.

Data analysis

Thematic content analysis of each transcription was done using an inductive approach. The analysis process was initiated by conducting open coding on transcripts derived from two FGDs and two SSIs by the PI (JGL) and another investigator (PPT) independently. They read through each transcript, line by line, and made notes of broad themes and potential categories identified. Afterwards, the themes and sub-themes identified were discussed and they reached an agreement on an initial codebook. The PI coded the remaining transcripts using ATLAS.ti 23 software and developed a comprehensive final codebook with categories and subcategories. To ensure validation, the other investigator independently coded additional transcripts using the aforementioned final codebook. The analysis was organised based on themes and participants' country of origin. The two sets of findings were then compared. Table 10 provides a summary of the themes and sub-themes from the FGDs and SSIs. The transcripts from both the FGDs and SSIs were coded and analysed together, ensuring a comprehensive examination of the data. Socio-demographic information of study participants was described using STATA 16 (StataCorp., 2019).

Table 10 Summary of the themes and sub-themes from the focus groups and interviews.

THEMES	SUB-THEMES
Theme 1: Understanding of health and illness	<ul style="list-style-type: none"> • <i>Health as the ‘absence of symptoms’</i> • <i>Health and illness as controlled by God’s will</i> • <i>Faith healing practices (e.g., spiritual treatments or religious rituals)</i>
Theme 2: Self-care and prevention attitudes	<ul style="list-style-type: none"> • <i>Prioritisation of family responsibilities</i> • <i>Low awareness of disease prevention (e.g., lack of interest/habit in regular check-ups)</i> • <i>Acceptance of early detection</i>
Theme 3 Self-care and prevention practices	<ul style="list-style-type: none"> • <i>Lifestyle practices (e.g., physical activity, healthy eating)</i> • <i>Religion as a self-care practice</i> • <i>Self-medication</i>
Theme 4 Motivators to engage with preventive care	<ul style="list-style-type: none"> • <i>Increasing awareness due to exposure to chronic diseases</i> • <i>Healthcare providers’ recommendation</i> • <i>Efficient call and recall system as facilitator</i>

Ethical considerations and consent to participate

Prior to their participation, all respondents were provided with comprehensive information about the study and study procedures, and were informed about the confidentiality of the study. Each participant willingly to participate gave written informed consent. The study was approved by the Research Ethics Committees of the London School of Hygiene and Tropical Medicine (26186), Bellvitge University Hospital (PR 140/22) and Vall d’Hebron University Hospital (PR(AG)317/2022). To acknowledge their contribution and to facilitate transportation, participants were compensated with a public transportation 10-trip pass.

Results

Participants' characteristics

Thirty-six women from the Moroccan community and thirty-seven women from the Pakistani community participated in either FGDs or SSIs. Participants' ages ranged from 24 to 65 years, with a median age of 40 years. Marital status varied among the participants, with 82.2% (N=60) reported being married. Nearly all the Pakistani women (97.3%, N=36) had children whilst among Moroccan participants, 77.8% (N=28) had kids. Half of the participants had been living in Spain for at least ten years (N=36), while approximately 10% (N=7) had arrived within the two years preceding the initiation of the study. The primary reason for migration to Spain among almost 85% (N=62) was family reunification. Pakistani women had a higher level of education than Moroccan women: 16 Pakistani participants had studied at university, while only four Moroccan women had. Nine participants had no education (7 from Morocco and 2 from Pakistan). Regarding employment, a significant majority of the women, 80,8% (N=59) were housewives and only 14 (12 from Morocco) were employed in either formal or informal jobs. In terms of Spanish language skills, approximately 37% of women (47.2% Moroccan and 27% Pakistani) reported not needing a translator during medical visits. Regarding religion, 90.4% of women considered themselves very or somehow religious and 97.3% identified themselves as Muslim. Up to 72.6% of the participants reported having been screened for CC at least once in their lifetime. Detailed information regarding participants' characteristics can be found in Table 11.

Table 11 Socio-demographic characteristics of study participants and screening status by country of origin (N=73).

	Total participants		Morocco		Pakistan	
	N	(%)*	N	(%)*	N	(%)*
Participants¹	73	(100%)	36	(49.3%)	37	(50.7%)
Age. median (IQR)²	42	(35-48)	39	(33-46)	40	(34-47)
Age groups						
24-34 years	18	(24.7%)	7	(19.4%)	11	(29.7%)
35-44 years	28	(38.4%)	13	(36.1%)	15	(40.5%)
45-54 years	19	(26.0%)	10	(27.8%)	9	(24.3%)
55-65 years	8	(11.0%)	6	(16.7%)	2	(5.4%)
Level of studies						
No studies	9	(12.3%)	7	(19.4%)	2	(5.4%)
Primary school	15	(20.5%)	9	(25.0%)	6	(16.2%)
Secondary school	25	(34.2%)	14	(38.9%)	11	(29.7%)
Vocational training	3	(4.1%)	2	(5.6%)	1	(2.7%)
University	21	(28.8%)	4	(11.1%)	17	(45.9%)
Employment						
Formal employment ³	10	(13.7%)	8	(22.2%)	2	(5.4%)
Informal employment/not regulated ⁴	4	(5.5%)	4	(11.1%)	0	(0.0%)
Unemployed or housewives	58	(79.5%)	23	(63.9%)	35	(94.6%)
Retired	1	(1.4%)	1	(2.8%)	0	(0.0%)
Marital status						
Single	4	(5.5%)	4	(11.1%)	0	(0.0%)
Married	60	(82.2%)	26	(72.2%)	34	(91.9%)
Separated or divorced	7	(9.6%)	5	(13.9%)	2	(5.4%)
Widowed	2	(2.7%)	1	(2.8%)	1	(2.7%)
Children						
Yes	64	(87.7%)	28	(77.8%)	36	(97.3%)
Number of children⁵						
1	6	(9.4%)	5	(17.9%)	1	(2.8%)
2	13	(20.3%)	6	(21.4%)	7	(19.4%)
3	20	(31.3%)	10	(35.7%)	10	(27.8%)
4 or more	25	(39.1%)	7	(25.0%)	18	(50.0%)
Time since migration to Spain						
<2 years	7	(9.6%)	2	(5.6%)	5	(13.5%)
2-5 years	11	(15.1%)	8	(22.2%)	3	(8.1%)
6-10 years	19	(26.0%)	4	(11.1%)	15	(40.5%)
>10 years	36	(49.3%)	22	(61.1%)	14	(37.8%)
Reason of migration						
Economic	1	(1.4%)	1	(2.8%)	0	(0.0%)
Family reunification	62	(84.9%)	27	(75.0%)	35	(94.6%)
Tourist/student visa	7	(8.2%)	6	(16.7%)	1	(2.7%)
Not reported	3	(2.7%)	2	(5.6%)	1	(2.7%)

	Total participants		Morocco		Pakistan	
	N	(%)*	N	(%)*	N	(%)*
Languages most spoken at home⁶						
Spanish or Catalan ⁷	14	(19.2%)	12	(33.3%)	2	(5.4%)
Arabic (Darija)	31	(42.5%)	31	(86.1%)	0	(0.0%)
Urdu	33	(45.2%)	0	(0.0%)	33	(89.2%)
English	5	(6.8%)	1	(2.8%)	4	(10.8%)
French	3	(4.1%)	3	(8.3%)	0	(0.0%)
Other ⁸	8	(11.0%)	3	(8.3%)	5	(13.5%)
Spanish language skills						
I always need a translator	20	(27.4%)	8	(22.2%)	12	(32.4%)
Most of the times I need a translator	8	(11.0%)	3	(8.3%)	5	(13.5%)
Sometimes I need a translator	11	(15.1%)	6	(16.7%)	5	(13.5%)
I do not need translator at all	27	(37.0%)	17	(47.2%)	10	(27.0%)
Self-perception of religiosity						
Very religious	23	(31.5%)	13	(36.1%)	10	(27.0%)
Somehow religious	43	(58.9%)	17	(47.2%)	26	(70.3%)
Very little religious	2	(2.7%)	2	(5.6%)	0	(0.0%)
Prefer not to answer	3	(4.1%)	2	(5.6%)	1	(2.7%)
Muslim self-identification						
Yes	71	(97.3%)	35	(97.2%)	36	(97.3%)
Prefer not to answer	1	(1.4%)	0	(0.0%)	1	(2.7%)
Public health insurance						
Yes	68	(93.2%)	34	(94.4%)	34	(91.9%)
No	2	(2.7%)	0	(0.0%)	2	(5.4%)
Cervical cancer screening status						
I don't know what CC screening is	4	(19.2%)	0	(0.0%)	4	(10.8%)
Never screened	14	(19.2%)	7	(19.4%)	7	(18.9%)
Ever screened	53	(72.6%)	27	(75.0%)	26	(70.3%)
Time since last cervical cancer screening						
<1 year	14	(19.2%)	8	(22.2%)	6	(16.2%)
1-3 years	21	(28.8%)	12	(33.3%)	9	(24.3%)
3-5 years	9	(12.3%)	2	(5.6%)	7	(18.9%)
>5 years	7	(9.6%)	3	(8.3%)	4	(10.8%)
Unknown	2	(2.7%)	2	(5.6%)	0	(0.0%)

* Column percentages; percentages may not add due to missing values.

¹ Percentages correspond to row percentages.

² Median and IQR were used as variable age was not normally distributed.

³ Includes full-time, part time and self-employment.

⁴ Includes only those reporting non-regulated remunerated work, working outside their homes.

⁵ Percentages were calculated among those women with children.

⁶ Percentages were calculated among the total participants for each language, as multiple options could be selected in the sociodemographic questionnaire.

⁷ Twelve women spoke Spanish at home. One woman reported only Catalan and another reported Catalan and Spanish as languages most spoken at home.

⁸ Includes Riffian (n=3), Kashmiri (n=1), and Punjabi (n=4).

Beliefs about health and illness

God's will and destiny

Both Moroccan and Pakistani women tend to share the Islamic view that life and death are granted by God and that individuals' fate is predetermined by God. For instance, a number of participants held the belief that being blessed with children is solely by God's will regardless of the use of modern family planning methods, such as contraceptive pills or intrauterine devices, among others, as well as getting treated for fertility issues. The following excerpts illustrate this belief:

"God has blessed me with a child after ten years (...) I had thyroid problems, my uterus was closed and it was down side and my eggs were not creating. They slowly started my treatment for two years and now by the grace of God I've a baby girl who is 4 years old and a baby boy" (FGD 1, younger Pakistani woman).

"(...) because pregnancy is God's will; even though I was taking the pill, I was pregnant for five months and I didn't know" (FGD 2, older Moroccan woman).

Similarly, both Moroccan and Pakistani respondents perceived God as the one who ultimately controlled health and illness, but also who provided the means to prevent, treat and cure the disease: "Every disease can be cured if God wants" (FGD 3, younger Pakistani woman). Referring to illness, women stated that "you cannot escape from what God brings you" (SSI MC10, older Moroccan woman). However, in both groups, women agreed that their faith did not hinder individuals from taking responsibility of their own health and from seeking appropriate care when necessary. Some respondents emphasized that God provided the medical options for healing and, therefore, it was the responsibility of individuals to utilise them:

"If God gives you a disease, you must accept it and fight it" (SSI MC07, older Moroccan woman).

"Allah himself has said that you should go for treatments" (FGD 2, younger and older Pakistani women).

“The fact that cancer is something that God brings you, it does not mean that you don’t have to take care of yourself, because prevention is better than cure” (FGD 0, older Moroccan woman).

“I believe in Him (God) and ask for His help, but I also take medicines and take care of myself, but I’m not afraid of death” (FGD 3, older Pakistani woman).

Two Pakistani respondents mentioned that in certain cultural contexts some people view disease as a direct punishment from God for sins committed. They stated that in Pakistan there are still individuals who believe that cancer and other illnesses are God’s punishment, implying that disease prevention can be achieved by avoiding sinful behaviours. Women of Moroccan origin did not provide any comment regarding this perspective. In fact, two of the Moroccan respondents did not make any mention of God throughout the individual interviews.

Spiritual prayers for healing and protection

Spiritual prayers for healing and protection continue to be practiced in Morocco and Pakistan. In both groups, some Moroccan and Pakistani women believed that engaging in ritual prayers and readings of the Qur’an may have health benefits. Several of the respondents reported making use of these spiritual rituals as complementary sources of healing to conventional medicine, as this Pakistani woman with an educational background in Economics explained:

“People are now less scared (of cancer) because there is chemotherapy, but there is also a verse (in the Qur’an) to listen to; it is called Surah Al Rahman; it is said that if we listen this verse three times a day, it helps to cure cancer (...) I heard that in England they give it to all patients muslims and non-muslims and they are recovering with these verses” (SSI PC03, older Pakistani woman).

Two respondents from Morocco also reported using spiritual treatments, such as *Ruqyah*, which consists of recitation of certain Quranic verses for healing, pain relief or protection against ‘evil eye’. Our findings also show the use of ‘transnational’ healers among Pakistani women. One participant explained that women not only consult (via phone) their families in Pakistan for advice on home remedies, but also to seek spiritual services from traditional healers in their home country.

While the mention of spiritual prayers was limited to a small number of participants, overall women believed in God’s power to protect them from and cure diseases. However, they emphasized the importance of complementing faith with appropriate medical options or vice versa: *“My mum tells me*

to pray; she says that you can cure yourself (by praying), but she also tells me to go to the doctor and take care of myself” (SSI MC11, younger Moroccan woman).

Self-care attitudes and practices

Self-care and women’s caregiver role

The prevailing sentiment among the respondents was that Moroccan and Pakistani women tend to neglect their own self-care. Instead, their priority and responsibility, or even “mission” according to one Pakistani woman, relies on taking care of their children, husbands and families. Their own well-being often takes a backseat with little importance given to their personal needs and self-care:

“We Pakistanis don’t take care of ourselves seriously, we take time out for the kids, but not for ourselves. We prepare meals for our husbands as well, but for ourselves, we don’t. We sacrifice ourselves” (FGD 3, younger Pakistani woman).

“A woman forgets about herself... she gets married and keeps busy with childcare, she forgets about herself, she is always the last thing” (FGD 1, older Moroccan women).

“We dedicate most of our time to our families and we don’t think about ourselves” (FGD 2, younger Pakistani woman).

Similarly, when the women discussed motivations and benefits of self-care, they primarily focused on the notion of taking care of themselves to ensure their ability to fulfil their responsibilities towards their families and homes, rather than focusing on personal benefit:

“I think (Pakistani) women should think about their health, as you are the main person (in the household) and things function through yourself. If you are healthy, then you can take care of them (husband and children) properly” (FGD 2, younger Pakistani woman).

“He (husband) always tells me that I need to take care of myself for them, that my children need me and that’s why I should take care of myself” (SSI PC03, older Pakistani woman).

“... she (Fatima) should have hope because of her children. She should go for treatment, she should go to the doctor and do all she can to stay with her children” (FGD 2, younger Moroccan woman).

Healthy lifestyle practices

The concept of self-care is often associated with adopting a healthy life-style, including engaging in physical activity and maintaining a healthy diet. The study participants showed little or no engagement with formal physical activities (e.g., jogging, fitness or swimming classes). Women described a discrepancy between their understanding of physical activity which was closely associated with daily living tasks and the concept of formal physical activity to maintain health, as advocated by health providers:

“Doctors ask us ‘drink water, eat salad and walk’. But all day what I do is walk as I’ve two grandchildren at home, so I’ve to go for the grocery, take them out, I don’t sit at home. I don’t walk like jogging but...” (FGD 3, younger Pakistani woman).

“The doctor said that I have to do exercise, you need to do sport for everything... I needed a solution (for her health problem), not doing sport. I do ‘exercise’ at home (referring to house chores), I don’t need sport” (FGD 2, younger Moroccan woman).

On the other hand, healthy eating was important for all participants. Both Moroccan and Pakistani women associated healthy eating with the consumption of homemade rather than processed food. However, it should be noted that this preference was partially influenced by the high prices of food:

“I do try to eat healthy. I try not to buy packed food, those high sugar foods and, instead, I try to buy natural food, such as vegetables, fruit and fish... I try not to bring home ‘bad food’ so they don’t get used to it” (SSI MC03, younger Moroccan woman).

“ (...) nowadays we don’t know what we eat (...) and if you are going to buy good food it is very expensive, so it is difficult...” (SSI MC01, older Moroccan woman).

Religion as a self-care practice

In addition to the discussion around a healthy life-style, when discussing the potential causes of Fatima’s CC, some participants in both groups emphasized that Muslim women do not smoke or consume alcohol. Consequently, they believed these could not be risk factors for developing cancer disease within their communities: *“We (Muslim women) don’t smoke or drink alcohol, so it can’t be because of that” (FGD 3, younger Moroccan woman).*

Some women mentioned that religious practices can serve as a form of protection against disease, *“religion cares for your health” (SSI PC06, younger Pakistani woman)*. For example, most women in both groups emphasized the value of virginity and marriage not only from a religious standpoint, but also as a self-care practice. However, this belief led to a lower risk perception of acquiring sexually transmitted infections (STIs), such as Human Papillomavirus (HPV) and reduced their awareness, as this Moroccan woman expressed: *“We (Moroccan women) don’t do as many check-ups as Europeans, because in general Europeans have many sexual relationships and they get this disease (HPV infection) more than us. We only have one relationship with our husband, so this doesn’t encourage us to go for check-ups” (FGD 0, younger Moroccan woman)*.

Self-medication

Once Pakistani women perceived themselves to be ill, they tended to self-medicate: *“We avoid going to the doctor and if we have any infection we take antibiotics and, if we feel pain, we take painkillers at home. We don’t visit them on time” (FGD 0, younger Pakistani woman)*. In contrast, a Moroccan woman referred to self-medication as an unhealthy habit: *“I avoid taking medicines as it is said they damage our kidneys and liver, so I only take what the doctor prescribes me” (SSI MC07, older Moroccan woman)*.

While many women from both countries had knowledge of herbal remedies, their use was not widespread. Participants combined traditional and Western medicine, and some even expressed scepticism regarding the effectiveness of herbal remedies to treat and cure disease:

“I don’t believe much in traditional medicine (...) It’s said that lavender with salt cures infections, I don’t know... In Morocco, people are used to heal with natural medicine, home remedies, and this kind of things and that’s because health care is expensive, medicines are expensive, so when they come to Spain they are already used to using natural remedies” (SSI MC09, younger Moroccan woman).

Knowledge and interest in disease prevention

Low awareness of disease prevention

Participants perceived health as the absence of symptoms, leading them to delay seeking medical care until the appearance of discomfort or symptoms such as severe pain, as this Pakistani woman illustrated: *“My mum always said ‘we have to take care of ourselves when there is a reason; before,*

you don't have to worry'" (SSI PC03, older Pakistani woman). For example, when asked why Fatima, the fictional immigrant woman diagnosed with CC, did not see a gynaecologist for eight years, many women in both groups answered that it was due to the lack of symptoms:

"We Moroccan women don't go to the doctor until we feel pain; we don't know that cancer disease can be silent" (SSI MC11, younger Moroccan woman).

Both Moroccan and Pakistani women reiterated that they tend to overlook their bodily concerns, leading to delays in seeking care and potentially receive a more severe diagnosis:

"We don't show much concern about what's happening with our bodies and, as a result, germs in our bodies keep growing and it's late by the time we come to know about that (cancer)" (FGD 0, younger Pakistani woman).

Both groups of women agreed that there was a lack of interest in regular check-ups, possibly explained by the fact that regular check-ups are not commonly practiced in their countries of origin as they are in Europe:

"We don't have the habit of doing check-ups (...) we don't give importance to our health... until we get ill" (FGD 2, younger Moroccan woman).

One possible explanation for the absence of this self-care habit may be the lack of a public health system in their countries of origin, as one Pakistani woman noted: *"because there is not a public health system (in Pakistan) and people don't have much money and the check-ups and tests are very expensive" (SSI PC07, younger Pakistani woman).* However, in the context of the Spanish health system where preventive care services are free of charge, another Pakistani participant suggested that some women may be unaware that these services exist and are free of charge:

"We don't have enough information, many people don't know that this tests exists. Even living here (Spain) we don't know" (FGD 3, younger Pakistani woman).

Another potential reason that emerged during the FGDs with Moroccan women was the fear of being diagnosed with a disease. In some cases, these women had personal experiences of cancer within their families and had witnessed the traumatic impact of cancer, which deterred them from attending regular check-ups:

“You don’t want to hear that you have cancer, it’s scary. So you tell yourself ‘better to leave it in God’s hands’” (FGD 0, older Moroccan woman).

In contrast, Pakistani women did not mention this fear, although some associated regular check-ups with the health of children and the elderly:

“Yes, they are useful to detect something, but at my age, I’m 39... when we are older we have more health problems, that’s when we visit the doctor and we do more check-ups” (SSI PC07, younger Pakistani woman).

Acceptance of screening for early detection

Although women showed limited awareness regarding the existence of asymptomatic diseases, the majority were familiar with the concept of early detection. There were differences between the two groups of respondents in their perception of the benefits of regular check-ups, particularly in relation to CC screening. Pakistani women felt more positive about the utility of preventive care services while in all FGDs with Moroccan women scepticism was expressed. In this sense, some participants expressed their concern about the time interval between screening tests, particularly in the case of HPV test, which is set at five years:

“I have a Spanish colleague in the office, she did the test (Pap smear) and it was ok, and six months later the cancer came out, so I think these tests are useless, because my colleague had to do the test once a year, but she did it and, between tests, in six months the cancer came out (...) so I don’t think early detection can protect from cancer” (FGD 0, younger Moroccan woman).

This sceptical view regarding the screening tests generated a rich discussion surrounding the importance of detecting diseases, particularly cancer, at an early stage, rather than in advanced stages, or when only the risk factor is detected. This fact was highlighted by one participant who tested positive for HPV: *“This is like fighting against the disease, even before it comes out. If you detect the disease in the beginning is not the same as when it is developed” (SSI MC05, older Moroccan woman).*

Changing perceptions

Increasing self-awareness

Some participants questioned the idea that Moroccan and Pakistani women do not prioritise self-care and their own well-being. Participants in the FGDs advocated for being more responsible with their own health and emphasized the importance of effectively managing their time as means of promoting self-care:

“This is not good, we should get time for ourselves as well” (FGD, Pakistani woman PG303, 36 years), because “if we are not healthy, how will we do other things?” (FGD 2, older Pakistani woman).

“Do you work? You can get an appointment and get time to go. Children? You can get an appointment when they are at school. We must organise our own time” (FGD 2, older Moroccan woman).

Throughout the FGDs and SSIs, certain women felt guilty for not taking responsibility for their own health: *“I am also getting sad that I’ve not gone to the gynaecologist for the last 22 years. We should go and get the tests done” (FGD 3, older Pakistani woman).* Although most women believed that seeking care in the healthcare system was only necessary when symptoms were present and a disease needed to be treated, a growing awareness was observed at the end of the interviews in both groups regarding the possibility of feeling healthy while having undetected conditions:

“People don’t have to wait until they are in pain to go to the doctor, they need to do check-ups from time to time, because there are diseases that don’t have symptoms” (SSI MC12, older Moroccan woman).

“... our mother-in-law was well, she was 80-something years old and she was ok, very active... but sometimes we don’t know what we have inside our bodies” (SSI PC01, younger Pakistani woman).

Interestingly, when participants were asked about what Fatima could have done to prevent the disease, the majority agreed that she should have gone for regular check-ups, showing an increasing awareness about the importance of early detection of a disease: *“If she would have done regular check-ups, then*

she could have known about it (cancer) at an initial stage, and her treatment could have been easier and earlier” (FGD 2, older Pakistani woman).

Motivators for screening

Women seemed to be more amenable to adopting life-style changes when they either had a chronic condition or had a personal experience of cancer or another severe disease within their families or close friendship circles.

“The first time that we gave importance to cancer was when my sister was diagnosed with breast cancer (...) then we were more aware and we started to get screened” (SSI MC01, older Moroccan woman).

“Before I didn’t take care of myself at all, but now because I have problems, I have a prosthesis so I cannot hold much weight (...) so I follow a diet, I eat healthy food, drink a lot of water and I also do some exercise” (SSI PC01, younger Pakistani woman).

Finally, both Moroccan and Pakistani women mentioned that receiving a direct invitation or request from a doctor or from the health system, such as call reminders or letters, would serve as a strong motivator for them to attend regular check-ups. One Pakistani woman even suggested the implementation of compulsory check-ups:

“They need to call me or send me a letter to my home and remind me that I need to take an appointment. Then, I would go (for check-ups), but if it has to be from my own initiative, I just keep telling myself ‘I’ll go, I’ll go;’” (SSI MC03, younger Moroccan woman).

“I think rather than an invitation, it should be an obligation if it is a really important test (...) We (Pakistani) are like this, until we are not obligated, we don’t go (...) But if they obligate, like with the COVID, then...” (SSI PC03, older Pakistani woman).

Discussion

As part of a broader research project to implement the new population-based CC screening programme in Catalonia, Spain, we conducted a study to enhance CC screening uptake among immigrant populations. We explored concepts of self-care and prevention from the perspective of Moroccan and Pakistani immigrant women living in Barcelona province. Our research unveiled

important factors to be considered to achieve successful implementation of CC screening in these study populations. Firstly, most of the study participants associated health with the mere absence of symptoms, leading them to only seek care for treatment when experiencing symptoms, rather than to prevent a disease. Secondly, they reported not being in the habit of doing regular check-ups, unlike many European women, and their self-care and prevention attitudes and practices seemed to be conditioned by cultural values. Lastly, they emphasized the need of an effective communication system to enhance their engagement and connection with preventive health services, specifically CC screening.

In our study, women represented health as ‘feeling healthy’ or not having symptoms. Therefore, the concept of self-care and prevention held little relevance for the majority, who reported taking care of themselves only when feeling unwell. This finding aligns with other studies on cancer prevention among different immigrant populations which found that women did not prioritise screening when feeling healthy (Marques et al., 2023; Alam et al., 2022; Tatari et al., 2020; Kowk et al., 2007; Borrayo and Jenkins, 2001).

Participants from both ethnic groups indicated that women in their home countries do not relate to the concept of self-care as many women would appear to do in Western countries nor have the habit of undergoing regular check-ups. This observation is consistent with other studies conducted in Spain with Pakistani women (Lansburgh et al., 2022) and with studies performed in Sweden encompassing diverse groups of immigrants, including women from North Africa and Asia (Grandahl et al., 2015; Olsson et al., 2014). The lack of self-care as a habit may be due to the cost of medical care in the immigrants’ home countries. Additionally, their lack of interest in self-care and prevention, including screening, could be influenced by their cultural understanding of these health concepts and their health practices. For example, a study conducted in Australia with Chinese immigrants found that self-care went beyond a simple focus on healthy life-style and emphasized the need to maintaining harmony and balance in their lives, and, going for medical check-ups was mainly for illness management rather than prevention (Kwok et al., 2007). In our study, we observed a similar pattern, where regular check-ups were sought only when women already had a chronic condition or when their perception of risk increased due to being exposed to cancer cases within their close circles. We also found that some women were sceptical regarding the benefit of screening due to the long intervals between tests and their own experiences of witnessing people getting ill despite having been screened.

In societies with traditional and patriarchal structures like Morocco and Pakistan, women play an important caregiver role that extends beyond their own families. In our study, most Moroccan and Pakistani immigrant women migrated to reunite with their husbands, some of whom continued living with their parental families in Spain. In this context, participants tended to prioritise the care of their

children and families over their own care, reflecting the value of self-sacrifice as an integral aspect of their caregiver role. In this sense, during the FGDs, a few respondents emphasized the importance of keeping healthy to fulfil their family responsibilities, suggesting that the individualistic concept of self-care often used in Western countries might be seen as ‘selfish’ behaviour and not being meaningful for specific populations. Previous studies have also identified this pattern of prioritising others’ needs over one’s own health or engaging in self-care to better provide care to others (Kowk et al., 2007). For instance, a study conducted with Somali refugees in the US highlighted how illness adversely affected women’s relationships and their role in the family (Carrol et al., 2007). This shows that the concept of self-care in more collectivist societies, where community interdependence and familial ties are highly reinforced, such as in Morocco and Pakistan, may not align with a more individualistic concept of self-care often used in Western societies and associated with healthy life-style activities, such as leisure time physical activity or regular health check-ups. This mismatch is evident in two studies that explored how culture and collectivistic families influence engagement in physical activity among Pakistani populations (Tariq, Rosten and Huber, 2022; Samir, Mahmud and Khuwaja, 2011).

In our study, Moroccan and Pakistani women primarily focused on healthy life-style choices related to food. They gave importance to consuming home-made, not processed food, aligning with Carrol et al.’s (2007) study on Somali refugees. On the other hand, only a very small number of women reported participating in any formal physical activity. Previous qualitative studies have also shown lower engagement in formal physical activity of Moroccan and Pakistani migrant women in the Netherlands (Nicolaou et al., 2012) and Spain (Lansburgh et al., 2022), respectively. This lower engagement may be because in some cultures it may not be customary to engage in leisure time physical activity (Beune et al., 2010; Hosper et al., 2008), and therefore, immigrant women would be less likely to participate in physical activities that are not related to their daily tasks. In fact, as in the Nicolaou et al.’s (2012) study, we found that two women from Morocco and Pakistan showed confusion regarding the distinction between physical activity associated with the tasks of daily life and leisure time or formal physical activity aimed to enhance health, considering the latter unnecessary.

Cultural and religious beliefs about health and illness can exert a significant influence on people’s health behaviours. We found that both Moroccan and Pakistani women believed that God ultimately controls health and illness and is the ultimate provider of healing. This finding aligns with previous research with Somali women in the US (Al-Amoudi et al., 2015) and the UK (Abdullahi et al., 2009), as well as with Moroccan women in Belgium (Ahaddour and Broeckaert, 2018), which found these religious beliefs and how not taking into account them in the design of prevention programmes may contribute to health inequities among Muslim populations (Padela and Zaidi, 2018; Padela et al.,

2012). Rather than a barrier to engage in self-care and prevention practices, women in our study emphasized individuals' responsibility to take care of their own health and use the means that God provides for prevention, treatment and cure. Other studies reflected a similar perspective among Moroccan women (Hamdiui et al., 2022a; Koudstaal, Verdonk and Bartels, 2020; Raymon et al., 2014) and suggested that religion might not be a significant barrier toward screening. We also identified the belief that disease can be a punishment from God for sins committed and 'evil eye'. However, only two women mentioned that in their home countries individuals from rural areas and with lower education still hold this belief, which is considered an integral part of maintaining good health, as explained by Jan and Smith (2007) in a study on self-care views among Pakistani immigrant families in the US.

The use of traditional medicine has a long history in Pakistan (Ahmad et al., 2021) and Morocco (Chaachouay et al., 2022). Studies have shown that ethnic minorities continue to use their traditional medicinal knowledge after migration to Western countries (Razam et al., 2017). However, in our study, we found that participants mostly used herbal medicines to complement biomedical medicine and a small number of women reported using spiritual treatments (e.g., religious prayers, health consultations to 'transnational' spiritual healers).

Our study has several potential limitations that need to be considered. Firstly, the findings reported here are part of a broader study aiming to improve cervical cancer screening uptake among Moroccan and Pakistani women, therefore general concepts of health and illness, and self-care and prevention have been simplified and tailored towards this aim. Nonetheless, they serve as a valuable groundwork for future exploration.

Secondly, it is important to mention that the sample criteria and recruitment strategy resulted in a high representation of specific groups. Second-generation immigrant women were excluded as the majority of them would not meet the age requirement for HPV-based CC screening in Catalonia, Spain, and women who were housewives were highly represented, especially in the Pakistani cohort. Thus, our results may not apply to women with formal employment who might also be more acculturated to the Catalan/Spanish society. Nevertheless, previous studies have shown that workforce participation by Pakistani women is generally low (Amber and Chichaibelu, 2023). In the case of the Moroccan cohort, around 33% of the participants had formal or informal jobs reflecting also the low integration into the Spanish labour market of the first-generation of Moroccan immigrant women (Kil et al. 2017, Cebolla and Requena, 2009). Thus, our sample is fairly representative of these groups.

Thirdly, the presence of research team members during the FGDs along with the fact that the SSIs were conducted by the PI and RAs who were second-generation immigrants may have influenced women to provide an opinion more closely aligned with a ‘Western’ viewpoint than they otherwise would have done, particularly, in regards to the influence of religion on their attitudes and behaviours concerning self-care and prevention. In anticipation of this, we addressed the religious questions after discussing other topics.

An important strength of this study is that the RAs and FGDs moderators shared a common background and language (Darija and Urdu) with the participants. This commonality proved to be very helpful in building rapport and fostering an environment in which the respondents felt comfortable to openly share their views. Also, a clear strength is the sample diversity. We were able to recruit women with a wide range of age and educational levels, and with different length of residency in Spain, as well as from the capital city and three other semi-urban areas, giving us the possibility of capture diverse views and experiences. The mixture of FGDs and SSIs enriched the data as it allowed us to capture the interaction between women and reactions about their own self-care and prevention attitudes and practices (Kitzinger, 1995), and more detailed accounts of individuals’ self-care and prevention experiences (DeJonckheere and Vaughn, 2019).

Conclusion

This study provides evidence on how concepts of self-care and prevention, often offered from a ‘Western’ perspective, may not fit into other conceptualizations of self-care used in more collectivist societies and that global self-care intervention guidelines may not be meaningful or motivating for people who have different understandings of health, illness, self-care and prevention. Moreover, it emphasises the importance of understanding prevailing cultural and religious values and beliefs in relation to health, self-care, and prevention, and how these evolve over time along with the exposure to new experiences and ideas needs to be incorporated into health promotion interventions. To be successful in improving the coverage of CC screening programmes and any other self-care intervention among immigrant groups will require more culturally appropriate strategies aligned with communities’ own perceptions and priorities. By embracing these approaches, healthcare systems can truly make meaningful progress in promoting equitable access and participation in such important preventive health initiatives.

Chapter 6: Social influences on Moroccan and Pakistani immigrant women's access and use of cervical cancer screening in Catalonia, Spain: a social network analysis

6.1 Introduction

Contrary to most health behaviour theories, which focus mainly on individual determinants, the socio-ecological model (SEM) argues that individual behaviours are influenced by multiple level factors. In this chapter, I focus the analysis at the interpersonal and community level, which refers to social influences from family, friends, acquaintances, and norms within social networks (McLeroy et al., 1988). The data presented in this chapter are a combination of qualitative narratives, numeric and visual network graphs corresponding to twenty-two participants. The use of multiple research techniques and, especially, egocentric social network analysis (SNA) methods, allowed me to obtain an in-depth understanding of the social world of these women and, specifically, to identify their main health information and advice networks, as well as influencing social norms within these networks. Therefore, this chapter addresses the second research question of the thesis - *How do social networks influence Moroccan and Pakistani immigrant women's preventive health behaviours, and specifically, their participation in CC screening programmes?* - by providing a description of the characteristics of women's social contacts and an exploration of the influencing roles of family ties, immigrant peers and male partners.

RESEARCH PAPER COVER SHEET

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SECTION A – Student Details

Student ID Number	LSH2004190	Title	Ms
First Name(s)	Jone		
Surname/Family Name	Garcia Lurgain		
Thesis Title	An ecological exploration of the barriers and facilitators to cervical cancer screening and HPV self-sampling acceptability among Moroccan and Pakistani women in Spain		
Primary Supervisor	Joanna Busza		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

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Where was the work published?			
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Where is the work intended to be published?	BMC Women's Health
Please list the paper's authors in the intended authorship order:	Jone G. Lurgain ¹ , Paula Peremiquel-Trillas, Hakima Ouaarab Essadek, Khadija Mellouki, Andleed Sarif and Guy Harling

Stage of publication	Undergoing revision
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SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I am the first author of this paper and I was responsible for study design and data collection, and I led on the analysis (with support from my supervisors Joanna Busza and Guy Harling) and interpretation of the data. I was also responsible of the conception of the paper and wrote the first draft of the manuscript, received feedback from all co-authors and responded. I led on the manuscript submission to the journal, and I will be responsible for responding to all reviewer comments and resubmission of the paper. This manuscript will be published with creative common licence CC-BY</p>
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SECTION E

Student Signature	Jone G Lurgain
Date	24 June 2024

Supervisor Signature	Joanna Busza
Date	24 June 2024

6.2 Abstract

Background: Participation in cervical cancer (CC) screening programmes is lower among immigrants compared to native women in many Western countries, in substantial due to lower knowledge and culturally influenced attitudes regarding self-care and prevention. Education and information programmes alone have limited impact on individuals' attitudes and behaviours, but may be bolstered by social influence methods such as peer support.

Methods: In this study, we combined self-reported quantitative structural social network data with qualitative narratives to describe the social context of 12 Moroccan and 10 Pakistani immigrant women living in Catalonia, Spain. We used a survey protocol and semi-structured interviews to explore how women's social contacts influence their CC screening behaviours.

Results: We identified strong gender and ethnic homophily in these women's social networks. Despite maintaining frequent remote contact with their family ties, their immigrant peers were more influential in providing health information and advice. Furthermore, the women's husbands played conflicting roles as health promoters and as barriers to the use of health prevention services.

Conclusion: Our findings highlight the need to incorporate tailored social influence approaches in the design of behaviour change interventions. In this case, the use of peer-based programmes to increase CC screening uptake among these two immigrant communities.

6.3. Research paper 2

Background

Although organised population-based screening programmes are intended to reduce health inequities, numerous studies report lower cervical cancer (CC) screening uptake among immigrant women compared to native women (Brzoska, Aksakal and Yilmaz-Aslan, 2020; Hertzum-Larsen et al., 2019; Møen et al., 2017). This disparity increases the risk of delayed diagnosis and treatment and ultimately lower chance of survival in an already-disadvantaged group. Multiple barriers to CC screening have been identified across populations and settings, but the two most salient factors for immigrant women's uptake of CC screening appear to be their limited knowledge about the disease, its causes and screening programmes, and culturally influenced attitudes toward self-care and prevention (Marques et al., 2023; Marques et al., 2020; Hamdiui et al., 2022a; Tatari et al., 2020). Since increasing awareness through access to education and information does not alone change health beliefs, attitudes and behaviours (Mittelmark, 1999), alternative or complementary approaches are needed.

One such alternative is the use of social influence methods to change individuals' thoughts, feelings or actions through people or groups important to them (Forgas and Williams, 2001). The concept of social influence forms part of many models of health-related behaviour, such as the theory of planned behaviour (Ajzen, 1991; Ajzen, 1985) and social norms theories (Cialdini and Trost, 1998), and has been used to guide preventive interventions, including CC screening. A key component of social influence on behaviour change relates to social norms. Social norms are unwritten and unspoken "rules and standards that are understood by members of a group, and that guide and/or constrain human behaviour" (Cialdini and Trost, 1998). Social norm theory posits two types of norms: beliefs about what others will approve or disapprove of in a given situation (injunctive norms) and beliefs about what others do in a given situation (descriptive norms) (Cialdini et al., 2006; Cialdini, Kallgren and Reno, 1991). Social norms about a health behaviour such as getting screened for CC - whether accurate or not - can act as a form of social influence if individuals adopt health behaviours based on either a perception that this is approved of by their social reference group (injunctive norms) (Ajzen, 1991; Ajzen, 1985) or the perceived prevalence of the behaviour among relevant peers (descriptive norms) (Marks and Miller, 1987).

Intention among women to participate in cancer screening programmes has been shown to be greater both when the perception that husbands, family, and close friends approve of screening and think they should do so (injunctive norms) (Griva, Anagnostopoulos and Madoglou, 2010; Allen, Stoddard and Sorensen, 2008) and when their close social contacts (e.g., sisters) were screened (descriptive norms)

(Keating et al., 2011). This means that individuals form opinions and beliefs about how they should behave through social interactions, observations, and information (Forgas and Williams, 2001) and these social influence processes occur within individuals' social networks.

Social networks provide the necessary structure for the transmission of knowledge and information, and the creation and diffusion of social norms that influence individuals' behaviours (Thoits, 2011). According to social network theory, the structure of a network (e.g., composition) may also influence and predict health behaviours and outcomes (Lin et al., 2019). An important distinction pertaining to network connections is that of strong and weak ties: the former are close relationships (e.g., with family and friends) and are important for emotional support, while the latter are more distant or casual relationships and are more valuable in terms of providing access to new information and opportunities (Granovetter, 1973). For instance, Luque et al. (2016) found that Peruvian Andean women with a higher proportion of weak ties, such as with neighbours in their immediate network were significantly more likely to get screened for CC than those with a higher proportion of family and friends.

In conclusion, individuals' health behaviours are likely to be influenced both by strong ties (e.g., family members) through injunctive and descriptive norms and weak ties (e.g. neighbours) or external information sources. Therefore, examining both social norms and social networks is crucial to deeply understanding social influence. Although several studies have explored the influence of social networks on immigrants' health behaviours and outcomes (Lin et al., 2020; Ye and Chen, 2020; Schoenmakers, Lamkaddem and Suurmond, 2017; Ralston and Escandell, 2012; Li and Wu, 2010), there is little evidence on how social networks may influence immigrant women's self-care and prevention attitudes and practices. We therefore carried out a qualitative egocentric social network analysis (SNA) through interviews with immigrant women from Morocco and Pakistan living in Catalonia, Spain. The study is nested within the new organised population-based CC screening programme implemented in this Spanish region and it aims to describe immigrant women's social networks and explore how network members may influence their self-care and prevention attitudes and, particularly, their CC screening behaviour.

Methods

Study participants and settings

Participants in this study were women born in Morocco or Pakistan who migrated to Spain after the age of 16 (thus not exposed to Spanish public education and, therefore, less influenced by the Spanish culture) and have lived in Spain for at least one year. The Moroccan community is the largest group of foreign immigrants in Catalonia (excluding Latin American immigrants), representing approximately

19% of the foreign population and 3% of the total population. Almost half of the Moroccan-origin residents in Catalonia are women (IDESCAT, 2022a), many of whom migrated to Spain through family reunification processes (Anthias, 2001). Many of them, especially first-generation immigrants, do not work outside the home; those who do work, often occupy precarious jobs (e.g., domestic work and hospitality industry) (Anthias, 2001). The Pakistani community is small in Spain but is rapidly increasing: between 2010 and 2020 it increased by approximately 72%, with over half living in Catalonia, especially in and around Barcelona (IDESCAT, 2022a; INE, 2022). Pakistani immigrant women comprise only 29% of this community (IDESCAT, 2022a) and mostly arrived through family reunification procedures predominantly sponsored by male family members (husband or father). Only a minority are active in the Spanish labor market (Güell et al., 2018).

Inclusion criteria for selecting the sample were the same as those used by the CC screening programme in Catalonia: women aged 25 or who will turn 25 in the year of the study, to 65 who have never been diagnosed with this cancer. We used purposive sampling to get maximum variability and snowball sampling techniques. The recruitment process took place both in Barcelona city and neighbouring municipalities with high concentration of these two immigrant communities. The recruitment process and collected data were part of a broader implementation study of an organised population-based CC screening programme in Catalonia, which included focus groups and semi-structured interviews. This is reported in greater detail elsewhere (Lurgain et al., 2024).

A total of 12 Moroccan and 10 Pakistani women were interviewed for this study. Recruitment of participants finalized when data saturation was reached. In addition, the final sample size was comparable to other qualitative and mixed-methods egocentric network studies targeting ‘hard-to-reach’ populations (Kenny et al., 2021; Wagner et al., 2018).

Study design

To explore the social networks in which the participants were embedded and how these may influence their health behaviours, we conducted a qualitative egocentric SNA, combining structural network data (e.g. size, composition, density) with qualitative narrative accounts. SNA is defined as a set of methods used for mapping, measuring, and analysing social relationships, and it is uniquely suited to describing, exploring, and understanding structural and relational aspects of health (Borgatti et al., 2009; Luke and Harris, 2007). Qualitative egocentric SNA, in particular, assesses the personal networks of an individual (‘ego’) across multiple social settings, by asking them to identify their network members - family, friends - referred to as ‘alters’ (Crossley et al., 2015). It also captures the meaning of these relationships and the extent to which these interactions can influence preferences, adherences to norms and decision-making (Hollstein, 2011).

Social networks' elicitation and alters' attributes

We adapted the methods employed by Lubbers, Molina and McCarty (2007) and Bidart et al. (2006, 2011) in order to study immigrants' and young people's social networks in Spain and France, respectively. After initial questions about sociodemographic and CC screening status, participants were asked to name their immediate social network with no limit on the number of individuals they could nominate to estimate network size and capture strong and weak ties (Neal and Neal, 2017). We used an interaction-based 'name generator' adapted from Lubbers, Molina and McCarty (2007) study: *'Please list the people, family members, friends or acquaintances whom you know by name or by sight, and with whom you had some contact in the past two years either face-to-face, by phone or by the internet and whom you could still contact if you had to'*. Participants responded to the 'name generator' sequentially for six contexts: family, friends, neighbourhood, leisure or educational activities, religious practice, and workplace, integrating the context-focused 'name generator' approach used in Bidart et al.'s (2006) study.

Respondents provided information about their contacts' attributes, e.g., sex, gender, country of origin, place of residence, and the nature of the ego-alter relationship. They were asked which contacts they would turn to for information and advice about CC screening, among other health-related questions; respondents could add individuals not already listed. They were also asked questions about social norms constructs, such as their female contacts' CC screening status (descriptive norms) and the proportion of 'alters' who ever recommended that they get screened (injunctive norms). Respondents ranked their alters by emotional closeness by placing them on a visual sociogram with three concentric circles: very close, close and distant. Finally, ego-perceived alter-alter ties were captured by drawing arrows between 'alters' believed to know each other. Interviewers made notes of the women's accounts about their interactions with their social contacts during the network elicitation (see complete protocol in Appendix 5).

Semi-structured interviews

Based on the visual sociogram, interviewers asked participants how their social networks had changed after migration and their perception of their new social networks in Spain. These questions served as a transition to a semi-structured interview (SSI) including questions to explore: a) the role of family and friends on participants' self-care attitudes and behaviours; b) women's access and use of health prevention services; c) the extent to which family and friends take part in women's health decisions, especially about sexual and reproductive health (SRH) issues, and d) their willingness to become 'champions' for CC prevention within their communities. These social influence questions were

embedded into a broader SSI topic guide addressing barriers and facilitators to CC screening published elsewhere (Lurgain et al., 2024). The topic guide was adjusted to explore emerging topics as data collection progressed. For example, we added a question to explore husbands' objections to their wives visiting a male doctor (see complete SSI topic guide in Appendix 6).

Data collection and trainings

Data collection was conducted between September and December 2022. The computer-assisted personal interviews used Network Canvas (Complex Data Collective, 2016), a social network-focused software that allows generation of quantitative measures, network visualizations and qualitative narratives (Birkett et al., 2021). Interviews were conducted either by the research assistants (RAs) (KM and AS) in Darija or Urdu, or by the first author (JGL) in Spanish. Interviews were conducted in private and quiet places, such as the participants' own home when their children were at school, participants' workplaces, the mosque or interviewers' homes. In some cases, the elicitation of the social network and the qualitative SSIs were conducted on separate days due to participants' busy schedules (e.g. childcare responsibilities). The interviews lasted between 1.5 and 2.5 hours. All interviews were audio-recorded and then translated and transcribed verbatim directly from the participants' local languages into Spanish or English. The RAs (KM and AS) received three days of training in SNA methods, Network Canvas software and interview topics and techniques, and conducted debriefs with JGL after each interview to discuss challenges and identify emerging topics and patterns.

Data analysis

We combined thematic content analysis with summary statistics and network graph comparison to first describe the social networks of these immigrant women and second, to understand how their social networks may influence their self-care and prevention practices relating to SRH and CC. For qualitative data analysis, we followed the 6-phase guide proposed by Braun and Clarke (2006). The first author (JGL) and another researcher (PPT) hand-coded two initial interview transcripts and after consensus of themes, the first author developed a final codebook with the help of ATLAS.ti (2023) and performed the content analysis. For SNA analysis, numeric data were cleaned and analysed in Stata16 (StataCorp, 2019). Network measures included network size (i.e., number of contacts listed), composition (i.e., proportion of network contacts who were female, immigrants, family members or were screened for CC) and density (the number of alter-alter ties present divided by all possible ties). We visualized each participant's network including ego-alter and alter-alter ties using the igraph package (Csárdi and Nepusz, 2006) in R software (R Core Team, 2021) and we used them to highlight

overall network patterns, differences between Moroccan and Pakistani women's networks and other factors predicting network composition and structure.

Ethical considerations

Ethical approval was obtained from the institutions participating in the study: London School of Hygiene and Tropical Medicine (26186), Bellvitge University Hospital (PR 140/22) and Vall d'Hebron University Hospital (PR(AG)317/2022). Written informed consent was obtained from all the participants prior to data collection. Participants were given a public transportation 10-trip pass to acknowledge their contribution in the study.

Results

Participants' characteristics

A total of 12 Moroccan and 10 Pakistani women were interviewed. Socio-demographic characteristics of participants are shown in Table 12. Most women lived in industrial semi-urban areas with long history of migration although nine lived in Barcelona city. Women's ages ranged from 24 to 65 years (median = 40 years). All but three participants (all Moroccan) were married with children. Pakistani women were more educated on average, although education levels in both groups varied greatly. Moroccan women had lived longer in Spain on average, but 80% of both groups had migrated over five years ago. Reflecting this longer residence, Moroccan women were more likely to be employed (42% vs 10%) and to speak Spanish or Catalan at home (33% vs 10%). Over 80% of participants had received a Pap test in their lifetimes, but many had not had a Pap test in the past three years.

Table 12 Characteristics of participants ('egos').

	Morocco		Pakistan	
	N	%*	N	%*
Participants	12	54.5**	10	45.4**
Age groups				
≤29 years	3	(25.0%)	2	(20.0%)
30 - 39 years	3	(25.0%)	4	(40.0%)
40 - 49 years	3	(25.0%)	2	(20.0%)
≥50 years	3	(25.0%)	2	(20.0%)
Level of education				
None	2	(16.7%)	1	(10.0%)
Primary school	1	(8.3%)	1	(10.0%)
Secondary school	5	(41.7%)	2	(20.0%)
Vocational training	2	(16.7%)	1	(10.0%)
College - University	2	(16.7%)	5	(50.0%)
Employment status				
Unemployed or housewives	7	(58.3%)	9	(90.0%)
Formal employment ¹	4	(33.3%)	1	(10.0%)
Informal employment/not regulated ²	1	(8.3%)	0	(0.0%)
Marital status				
Single	3	(25.0%)	0	(0.0%)
Married	8	(66.7%)	10	(100.0%)
Divorced	1	(8.3%)	0	(0.0%)
Has children³	9	(75.0%)	10	(100.0%)
Time since migration to Spain				
<2 years	0	(0.0%)	1	(10.0%)
2-5 years	2	(6.7%)	1	(10.0%)
6-10 years	2	(16.7%)	5	(50.0%)
>10 years	8	(66.7%)	3	(30.0%)
Languages most spoken at home				
Spanish or Catala	4	(33.3%)	1	(10.0%)
Arabic (Darija) or Urdu	9	(75.0%)	8	(80.0%)
English	1	(8.3%)	3	(30.0%)
Other ⁴	2	(16.7%)	3	(30.0%)
Religion (Muslim) self-identification				
Very little	2	(16.7%)	1	(10.0%)
Somehow	7	(58.3%)	5	(50.0%)
A lot	2	(16.7%)	4	(40.0%)
Prefer not to answer	1	(8.3%)	0	(0.0%)
Number of years since las Pap smear				
<1	0	(0.0%)	1	(10.0%)
1 to 2	3	(25.0%)	2	(20.0%)
2 to 3	4	(33.3%)	1	(10.0%)
3 to 5	1	(8.3%)	4	(40.0%)
5 or more	1	(8.3%)	1	(10.0%)
Never screened	3	(25.0%)	1	(10.0%)

*Column percentages; may not sum to 100% due to missing values. **Participants' percentages correspond to row percentages. ¹Includes full-time, part time and self-employment. ²Includes only those reporting non-regulated remunerated work, working outside their homes. ³Percentages were calculated among those women with children. ⁴Includes Riffian (n=2), and Punjabi (n=3), for Moroccan and Pakistani women, respectively.

Moroccan and Pakistani immigrants' social networks

Size and composition of participants' networks

The 22 participants named a total of 485 social contacts, with an average of 22 contacts (range: 6 - 38) per participant, among both the Moroccan and Pakistani women. Social network composition was very similar in both groups, as shown in Table 13. Most of the social contacts were female (78%, N=379) and were born in the participants' country of origin (75%, N=367) or in third countries (6%, N=29), showing a strong gender and ethnic homophily (e.g., 'egos' and 'alters' were similar to one another in these terms).

Respondents had few contacts born in Spain (17%, N=84), as seen in their network graphs (Figure 5), but Moroccan women had twice as many Spanish contacts as Pakistani women. This difference reflected Moroccan women's greater integration in the Spanish labour market – all employed participants' networks contained Spanish colleagues. In contrast, almost half of the contacts (49%, N=236) were close ties, such as family, and of these more than half (57%, N=135) were parents, siblings and other close relatives (e.g., cousins and aunts) living in their home countries.

Friendship ties comprised around a quarter of all contacts (25%, N=124) with most of them (N=91) living in Catalonia, reflecting the new relationships that women built in Spain and the significance of residential proximity for access to information and advice. Qualitative data highlighted that some close relationships reflected multiple roles: e.g., women considering their siblings, sisters-in-law, cousins, and husband as friends. Finally, women named almost as many acquaintances (weak ties) (26%, N=125) as friends (close ties) in their social networks. These weak ties were mainly women's Spanish colleagues and neighbours, children's teachers, health providers and immigrant peers.

Interactions' patterns and connectedness between ties

Strong ties, such as husbands and children were the contacts with whom participants communicated most regularly (daily) and in person. Most interactions with acquaintances (e.g., colleagues, neighbours, teachers, other mothers in the park, healthcare providers) were in person and quite regular (daily or weekly). As mentioned earlier, Moroccan and Pakistani participants seemed to speak with their parents (especially mothers), siblings and friends regularly but mainly through phone and online chat (Table 13).

Most participants had dense social networks (almost half of all possible alter-alter ties existed), which may be explained by the high proportion (almost 50%) of family members in the women's networks. This was even more apparent in the two consanguineous marriages (of first cousins) as is shown in Figure 5 in the Moroccan participant MC10's graph. Moroccan and Pakistani women mentioned an average of 9 close ties (placed in the inner circle of the sociogram), representing nearly 42% of the total alters.

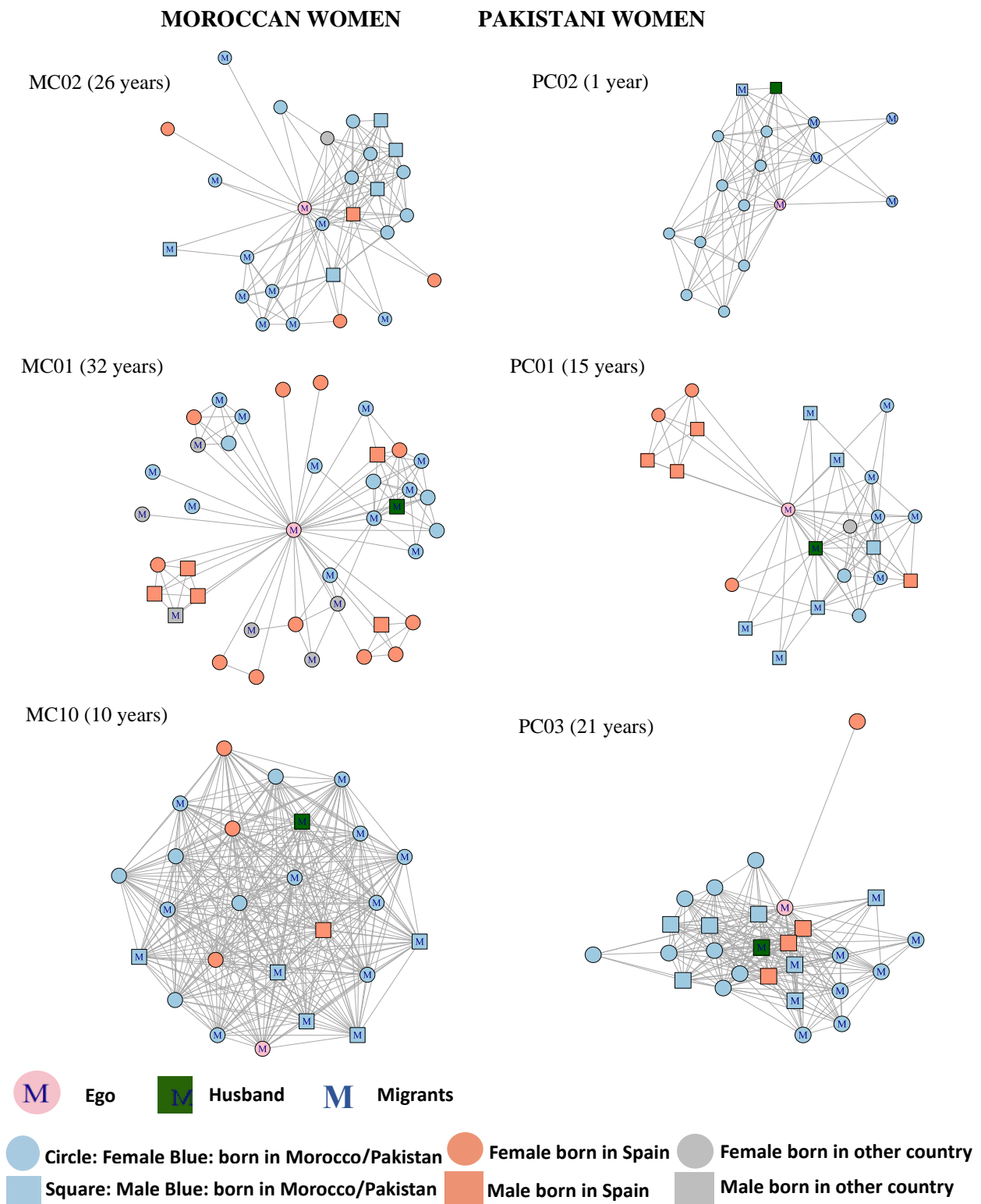
Table 13 Composition of social networks ('alters') by ego's country of origin.

	Moroccan women ('egos') (N=12)		Pakistani women ('egos') (N=10)		Total 'egos' (N=22)	
	N	%*	N	%*	N	%*
Total contacts ('alters')	264	(54.4%)	221	(45.6%)	485	(100%)
Gender						
<i>Female</i>	211	(79.9%)	168	(76.0%)	379	(78.1%)
Age						
<i>≤29 years</i>	65	(24.6%)	55	(24.9%)	120	(24.7%)
<i>30-39 years</i>	62	(23.5%)	74	(33.5%)	136	(28.0%)
<i>40-49 years</i>	65	(24.6%)	45	(20.4%)	110	(22.7%)
<i>≥50 years</i>	72	(27.3%)	47	(21.3%)	119	(24.5%)
Education level						
<i>None</i>	40	(15.2%)	9	(4.1%)	49	(10.1%)
<i>Primary school</i>	34	(12.9%)	12	(5.4%)	46	(9.5%)
<i>Secondary school</i>	56	(21.2%)	46	(20.8%)	102	(21.0%)
<i>Vocational training</i>	22	(8.3%)	22	(10.0%)	44	(9.1%)
<i>University studies</i>	90	(34.1%)	100	(45.2%)	190	(39.2%)
<i>Koranic school</i>	4	(1.5%)	2	(0.9%)	6	(1.2%)
<i>Don't know</i>	18	(6.8%)	30	(13.6%)	48	(9.9%)
Country of birth						
<i>Morocco/Pakistan</i>	188	(71.2%)	179	(75.7%)	367	(75.7%)
<i>Spain</i>	56	(21.2%)	28	(17.3%)	84	(17.3%)
<i>Other</i>	18	(6.8%)	11	(6.0%)	29	(6.0%)
<i>Don't know</i>	2	(0.8%)	3	(1.0%)	5	(1.0%)
Country of residence						
<i>Morocco/Pakistan</i>	61	(23.1%)	74	(33.5%)	135	(27.8%)
<i>Spain</i>	188	(71.2%)	129	(58.4%)	317	(65.4%)
<i>Other</i>	14	(5.3%)	18	(8.1%)	32	(6.6%)
<i>Don't know</i>	1	(0.4%)	0	(0.0%)	1	(0.2%)
Relationship of contact to respondent						
<i>Son/daughter</i>	20	(7.6%)	13	(6.8%)	33	(6.8%)
<i>Husband/partner</i>	8	(3.0%)	10	(3.7%)	18	(3.7%)
<i>Mother/father</i>	8	(3.0%)	8	(3.3%)	16	(3.3%)

<i>Siblings</i>	35	(13.3%)	33	(14.0%)	68	(14.0%)
<i>Other relatives¹</i>	40	(15.2%)	24	(13.2%)	64	(13.2%)
<i>Husband's relatives</i>	17	(6.4%)	20	(7.6%)	37	(7.6%)
<i>Friends</i>	67	(25.4%)	57	(25.6%)	124	(25.6%)
<i>Acquaintances²</i>	69	(26.1%)	56	(25.8%)	125	(25.8%)
Frequency of contact						
<i>Daily</i>	90	(34.1%)	76	(34.4%)	166	(34.2%)
<i>Weekly</i>	84	(31.8%)	64	(29.0%)	148	(30.5%)
<i>Monthly</i>	34	(12.9%)	48	(21.7%)	82	(16.9%)
<i>Less than once a month</i>	56	(21.2%)	33	(14.9%)	89	(18.4%)
Channel of communication						
<i>In person</i>	91	(34.5%)	90	(37.3%)	181	(37.3%)
<i>Phone</i>	43	(16.3%)	41	(17.3%)	84	(17.3%)
<i>WhatsApp or similar</i>	130	(49.2%)	89	(45.2%)	219	(45.2%)
<i>E-mail</i>	0	(0.0%)	1	(0.2%)	1	(0.2%)

*Percentages correspond to row percentages. ¹Other relatives refer to other women's close relatives, such as cousins, aunts. ²Acquaintances were colleagues, neighbours, children's teachers, health providers, other immigrant peers.

Figure 5 Examples of social networks of the study participants and length of stay in Spain.



The top two network graphs illustrate the common tendency of gender and ethnic homophily in the Moroccan and Pakistani women’s social networks. The two graphs in the middle are examples of the

social networks with the presence of job-related clusters of Spanish female and male contacts. The two graphs at the bottom show the high density of the women's networks, all contacts know each other.

Expansion of women's social networks in Spain

Despite women's narratives focusing on how their networks have decreased since migrating to Spain, both as a result of their distance from family and friends, but also because of their changing life circumstances (e.g., becoming wives and mothers for the first time), in fact, when asked to quantify and depict their social relationships, women reflected much wider social networks than they themselves initially perceived. The study participants explained how they built these new relationships in Spain, mostly with other female immigrants from their home countries. Since most women from both groups were housewives and mothers, their social interactions were mainly limited to the domestic sphere and public spaces where they took their children, e.g., schools and parks. Another context where women had the opportunity to build new relationships was the mosque, suggesting also a potential homophilic tendency based on religion. Whereas most Pakistani participants reported attending social events at the mosque, only two Moroccan women reported participating in any activity organised at the mosque, despite most of them agreeing that many women in their community often participate in mosque activities.

Participants' new social networks in Catalonia, Spain, were also shaped by their personal characteristics (e.g., age) and circumstances (e.g., marital and employment status). For instance, having a job was an important determinant of women's networks expansion. As this employed participant from Pakistan explained, her new network in Spain was more diverse than the one in her home country: *"I never thought that I could have male friends... For us, it's a very big thing! We can have female friends but not male friends. Now I do have a male friend and I am happy and satisfied"* (PC01).

The role of social networks on self-care and preventive health behaviours

Normative Influences on CC screening

Descriptive norms regarding CC screening differed between Moroccan and Pakistani participants: Moroccan women believed that half of their female contacts had been screened, compared to one-third for Pakistani participants (Table 14). However, injunctive norms were very similar, with both groups believing that around one-third of the contacts would want them to get screened, and 15.9% of contacts had advised participants to get screened.

Table 14 Normative influences on cervical cancer screening by participant cohort.

	Moroccan women (‘egos’) (N=12)		Pakistani women (‘egos’) (N=10)		Total	
	N	%*	N	%*	N	%*
Total ‘alters’¹	264	(54.4%)	221	(45.5%)	485	100.0%)
Do you think this person has ever undertaken a Pap smear?²						
<i>Yes</i>	105	(49.7%)	58	(34.5%)	215	(44.3%)
Do you think this person thinks you should undertake a Pap smear?						
<i>Yes</i>	96	(36.4%)	65	(33.2%)	161	(33.2%)
Has ever this person recommended you undertaking a Pap smear?						
<i>Yes</i>	42	(15.9%)	30	(13.6%)	72	(14.8%)

*Percentages correspond to column percentages. ¹Percentages correspond to row percentages.

²Percentages were calculated only among female contacts.

Female family and immigrant peers

Data from the qualitative interviews confirmed the gender and ethnic homophily identified in the egocentric network analysis. Most women highly valued the consultation and advice of close ties for health-related decisions, particularly in the context of self-care and prevention practices. They expressed a special trust and comfort in discussing health matters with other female close contacts, although their preferences for information and advice networks varied depending on the health topic. For instance, participants in both groups identified family members as the primary source of encouragement for self-care practices, such as exercise or maintaining a healthy diet. Nonetheless, when dealing with more sensitive and intimate health issues, such as gynaecological problems, it seems that women preferred to seek advice from their immigrant peers, meaning those new ‘friendships’ formed with other women in their children’s school, parks, mosques, and other public spaces since their arrival in Catalonia (weak ties), including at times in-laws and relatives. One Pakistani woman explained that they always avoided causing worry to their families (especially, mothers) back home about their health problems, and that they also found it challenging to discuss women’s health issues with male relatives due to social taboos. Moroccan and Pakistani participants describe below what type of health information, advice, and experiences they often share with their immigrant peers:

“Most of my friends here are my age and we have similar health issues and experiences. We share our intimate things (...) I trust them, they are friends. These intimate things cannot be shared with all people. And with men, never! Because I can’t ask men for advice about the female reproductive system” (PC03)

“We always talk about our things. She [her friend] also has itching (in her genitals) and me too... I remember the last time we were together; she told me that the itching is due to a bacterium that her husband got and she told me that one day she asked her husband: “are you going to meet someone tonight?” And he said: “no”. She told me that she was scared of men, because they go out a lot and she was afraid of men coming back home with a disease. So I tried to calm her and told her not to be worried” (MC04)

“One friend told me ‘But where do you live? I have put an IUD ‘down there’ and every year I do a check-up’. She told me that she didn’t have her period for two months and when I told her about this cervical cancer, she was afraid of it” (PC05)

Interestingly, when women were asked who would they ask for advice before undergoing CC screening, they mentioned healthcare providers first (e.g., doctors, nurses, pharmacists, medical students). Notably, many of these professionals were relatives belonging to their immediate social networks:

“I always ask my auntie because she is a doctor in Morocco, and she knows about all these things [gynaecological check-ups]” (MC11).

On the other hand, the vast majority of women highly valued the advice and experiences of other female immigrant peers regarding health prevention services in Catalonia, especially those women who had been living in Spain for a longer time, and those who had been married and had children. Particularly, when women were asked from whom they would seek help to use an HPV self-sampling device, they once again emphasized the importance of learning from experienced peers who had already used the device and were familiar with navigating the Catalan health system.

“I would ask my sister-in-law about cervical screening and this test [HPV self-sampling] because she has done it before and has experience about it” (PC06)

“I would ask advice from my cousin and also from my husband’s sister and my mother-in-law, because these people live here and they understand better and can guide me better than

my family in Pakistan; even if they are health workers, I prefer people who live here (Spain)”
(PC12)

Finally, most participants from both groups expressed their willingness to become ‘champions’ of CC prevention, encouraging and helping other women to use HPV self-sampling devices: *“In our communities, we always pass valuable information to others, if one person knows about this cancer test, she talks about it to another and this one to another one, and so on”* (MC04).

The role of the husband

The multiple roles of the husband in the lives of Moroccan and Pakistani participants in Catalonia, Spain, were present implicitly and explicitly throughout the qualitative interviews. Particularly, we identified conflicting influences of the husband: as a health promoter and as a barrier to health service use.

Participants in both groups highlighted the emotional and economic support, as well as the guidance provided by their male partners (close ties) during the first years after migrating, particularly in navigating the Catalan health system: *“My husband used to come with me to the doctor, he taught me where was everything, what I had to do to go alone to the doctor... He was the only one who supported me in the beginning”* (MC03). Participants also emphasized how their husbands encouraged them to self-care and access health prevention services:

“When I’m tired or I don’t feel well, my husband tells me directly to do a check-up. He always tells me: “If you don’t make the appointment, I’ll do it for you”, then I do it myself”
(MC04)

“He always tells me that I need to do regular check-ups, because he always says that we need to know whether we have a disease asap, so that we can seek a solution, or the doctor can tell us how we need to take care of ourselves or what we can do” (PC03).

Although the above narratives show a supportive role in husbands concerning their wives’ overall health, male partners appeared poorly engaged in women’s SRH issues, except when they were pregnant, or the couple faced fertility problems. Some women explained that these topics are not shared with males in their cultures, but, paradoxically, in our study we identified an important limiting role of some husbands who seemed to prevent women from access to and use of gynaecological preventive health services, for instance, by not giving them permission to visit a male doctor, as these participants’ accounts show:

“Someone told me that his wife didn’t visit the gynaecologist until her waters broke. When she went to the hospital here in Terrassa her husband asked for a female doctor to attend his wife (...) and the doctor told him that there was not a female doctor in that moment, but he insisted: ‘she’s my wife and I don’t want a man to help my wife to give birth’. Eventually, the husband was asked to leave the hospital and doctors attended the woman” (MC05)

“It can be the case, but these are men from rural areas with low education, they think ‘if a man touches my wife, it will be sinful’” (PC07)

“There are cases... there was a woman in my neighbourhood in Morocco who didn’t go to any check-ups, the doctor had to be a female, otherwise she didn’t go... It may be the case that her husband didn’t allow her to go” (MC06)

Finally, we observed different levels of autonomy in terms of SRH decision-making between Moroccan and Pakistani women. Whereas most Pakistani participants reported making all their health decisions together with their partners, Moroccan participants considered women’s health issues as personal and many of them emphasized that the decision on whether or not to get screened for CC was theirs to make. The below excerpts illustrate this:

“I consult everything with my husband” (PC07)

“I wouldn’t ask for advice to anyone, it’s not necessary. I’d just inform them (family) that I got an appointment with my gynaecologist, that’s it” (MC12)

Discussion

In this study we examined how the transmission of advice and social norms within Moroccan and Pakistani immigrant women’s social networks in Catalonia, Spain affects their preventive health behaviours, especially regarding CC screening. First, we found that female immigrants from the participants’ country of origin dominate Moroccan and Pakistani women’s social networks. Second, although frequent remote contact with their close family ties was reported, these women’s most influential reference groups for SRH matters were weak ties, such as their immigrant peers in Spain, including in-laws and other relatives. Third, despite female contacts dominating the core information and advice function in participants’ networks, husbands play a prominent role in facilitating or constraining women’s access to and use of health services, including CC screening.

The strong gender and ethnic homophily seen in these Moroccan and Pakistani women's social networks is consistent with previous research conducted with different immigrant populations (Zhao, 2023; Vacca, Cañarte and Vitale, 2022; Van Tubergen, 2015; Rostila, 2010). This homophily influences the information these women receive from others, as well as their attitudes and health-related decision-making, and may arise from at least two sources. First, community social norms, such as sex segregation and gender roles of women (i.e., mothers, housewives) shape participants' social interactions and the composition of their social networks. Notably, our findings show how participants' new relationships were mainly developed at children's schools, in parks and mosques (where sex segregation is the norm). Second, ethnic homophily may reflect the length of stay and proficiency in the majority language in the host country (Titzmann et al., 2016; Titzmann and Silbereisen, 2009). However, our study does not support this evidence, as most participants show a strong ethnic homophily despite having high Spanish language proficiency and living for a long time in Spain. An alternative explanation in these groups may be proximity (we are more likely to have contact with those who are closer to us), given the high concentration of immigrants in specific residential areas of Barcelona province. This hypothesis aligns with evidence from Scotland that movers tend to be drawn to areas with higher concentrations of ethnicities similar to their own (Bakens and Pryce, 2019).

Moroccan and Pakistani women mentioned an average of 9 close ties, representing nearly 42% of the total contacts, which may respond to the cultural context. Family relationships are the most important component of social life in Moroccan and Pakistani societies, where people often live in multigenerational households and, therefore, have social networks mainly composed of close family ties. Respondents valued consultation with their families back home before making a health decision. Nonetheless, for more private issues relating to SRH, participants reported a high degree of trust in weak ties, such as their female immigrant peers, reflecting the above ethnic homophily and the strength of weak ties (Granovetter, 1973).

Women highlighted the importance of learning from those peers with more experience in Spain and better understanding of the Catalan health system and particularly the CC prevention services. This exchange of health knowledge between immigrant women was also reflected in a study conducted in the US with women from Guatemala (Menjívar, 2002). Contrary to other migrant studies in Sweden and China (Åkerman et al., 2016; Li and Wu, 2010) which associated ethnic homophily with inadequate access to and use of health information and services, in our study we identified an opportunity to leverage newly formed, but still ethnically homophilic, peer connections to replace older normative views about preventive health behaviours with new ones. These peer connections may definitely improve access and use of healthcare services, including CC screening uptake. This

approach is aligned with recent implementation studies conducted in Uganda, Canada, and the US, in which researchers used peer-based interventions to promote and increase uptake of CC screening (Devotta et al., 2023; Wanyenze et al., 2022; Luque et al., 2017). In our study, most participants expressed their willingness to become ‘champions’ of CC prevention, suggesting that word-of-mouth communication may also be crucial for information transmission in these two communities, especially to reach those women who are more isolated.

The important role that male partners play in women’s health decision-making could override the opportunity that these immigrant peers offer to the participants to access new health information and dissemination of adapted norms around screening, with beneficial (if the husband is particularly supportive of preventive health behaviours) or negative effects (when the husband poses barriers to accessing health care). For instance, participants emphasized their husbands’ role as health promoters providing examples in which they encouraged women to self-care to prevent or manage chronic conditions. This health promoter role was not so obvious, however, when it came to SRH matters, which echoes the lack of engagement of husbands in CC prevention among Muslim families in Indonesia (Widiasih and Nelson, 2018).

On the other hand, women reported the constraining role that conservative male partners can play in not giving their wives permission to visit a male doctor. This important barrier to women’s access and use of healthcare services has also been identified in other studies conducted recently on CC screening uptake among under-screened women (Devotta et al., 2023; Vega-Crespo et al., 2022; Lau et al., 2022). To date, a growing body of studies conducted mainly in low- and middle-income countries has explored the potential engagement of husbands in CC screening interventions aiming to increase women’s uptake (De Fouw et al., 2023; Dsouza et al., 2022a; Okedo-Alex et al., 2020; Binka et al., 2019). However, further research is needed to better understand male partners’ social norms around spousal support for preventive health behaviours and to evaluate the inclusion of men in CC screening interventions, especially in Western countries.

We also explored potential influences of injunctive and descriptive norms on CC screening behaviours. Only 15% of contacts had ever recommended that women participants get screened and this percentage corresponds mainly to siblings and immigrant peers, which reinforces their potential influence on CC screening uptake. On the other hand, while Moroccan participants believed that 50% of their female contacts had been screened, Pakistani women believed that only 34% of their female contacts had done so, which could be linked to the different levels of autonomy regarding SRH decision-making shown between Moroccan and Pakistani participants.

In sum, our findings point to how immigrant women's experience of social influences and how their sources of information and advice change over time. Women rely heavily on close ties, such as their husbands when they first move and settle into Spain, but over time, often without noticing, many participants expanded their social networks and created trusting relationships with other female immigrant peers. This had the impact of expanding support sources for SRH matters beyond the husbands' sphere to also include their immigrant peers (weak ties) in Spain. There are changes across time and space that are relevant to engaging with the health system, and therefore, possible ways to leverage those new relationships and connections for positive change in relation to screening behaviours among immigrant populations and, particularly, Moroccan and Pakistani women living in Catalonia. For instance, engaging those immigrant peers who have had longer exposure to and more experience with the Catalan health system in the transmission of health information and new norms related to preventive health behaviours, in this case, to increase CC screening uptake, would be an effective approach.

The study presents several strengths alongside certain limitations. The most salient strength is the combination of multiple research methods and the triangulation of data: egocentric network measures, graphs, and narrative accounts. This comprehensive approach offers a greater depth of understanding regarding the social networks within which Moroccan and Pakistani immigrant women are embedded, shedding light on the potential influences of these social relationships on women's health behaviours. In terms of limitations, the sample size of 22 immigrant women restricts the measurement of the effect of informational and normative influences on participants' behaviour, a consideration beyond the scope of this egocentric formative research. Nevertheless, it establishes a foundation for future survey studies. Moreover, the adoption of a maximum variability sampling approach allowed for meaningful comparisons between women's social network patterns. Also, the use of multiple languages (Spanish, Darija-Arabic, Urdu) might have influenced the elicitation of different social networks. In the anticipation of this issue, the two bilingual RAs underwent comprehensive training to ensure consistent understanding of question meanings across languages. Furthermore, using all three languages for interviews facilitated outreach to a wider spectrum of immigrant women, including those proficient in Spanish. Finally, acknowledging the potential respondent burden in social network studies, efforts were made to minimize participants' fatigue and avoid losing their attention and motivation, which affects the quality of data (adams, 2019). To mitigate this, the protocol was kept as short and concise as possible, incorporating breaks, and, in some cases, conducting the SNA data collection and the qualitative interview on separate days to ensure data quality.

Conclusion

This study provides valuable evidence on the need for social influence approaches to behaviour change for the effective design of health promotion interventions. Particularly, in the context of the new Catalan population-based CC screening programme implementation, this study emphasizes the imperative of leveraging the social networks of migrants. The strategic utilization of social networks is crucial not only for disseminating accurate information on CC prevention, but also in fostering a shift in perceptions and health prevention behaviours within these communities. Furthermore, the study identifies a significant research gap related to the potential role of male partners in enhancing women's CC screening uptake. A deeper understanding of men's social norms concerning the support of women's preventive health behaviours is needed. Such insight will offer an opportunity to assess the feasibility to incorporate male partners into future CC screening interventions in Catalonia, Spain, and beyond. This holistic study acknowledges the interconnectedness of social networks and the need for inclusive strategies in promoting women's health within immigrant communities.

Chapter 7 Exploring cultural competence barriers in the primary care sexual and reproductive health centres in Catalonia, Spain: perspectives from immigrant women and healthcare providers

7.1 Introduction

In Chapter 6, I described the social interactions of Moroccan and Pakistani immigrant women beyond the health system (i.e. interpersonal relations) and how these may influence health behaviours. In this chapter, I move to a health system level analysis, examining the intercultural competence of the Catalan health system through the perceptions and experiences shared by Moroccan and Pakistani immigrant women and healthcare providers. Guided by Betancourt et al.'s (2003) framework, I present three major levels of healthcare in which intercultural communication barriers between patient and provider may occur and contribute to health disparities: first, clinical barriers, which refer to the direct interaction and relationship between providers and patients and they occur when there are linguistic limitations and cultural differences that are not accepted and well understood; second, structural barriers, which refer to the availability of trained interpreters and culturally/linguistically appropriate health education materials and, third, organisational barriers, which are related to the representation of racial/ethnic minorities in healthcare workforce.

The data presented in this chapter were analysed qualitatively combining inductive and deductive approaches, and provide a detailed description of the communication barriers due to language limitations and cultural differences between Moroccan and Pakistani women and healthcare providers. The presentation of patients' and providers' narratives together assist understanding of the needs, expectations and attitudes of both sides. This chapter also provides a succinct list of recommendations to improve intercultural communication based on women and healthcare professionals' narratives.

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	LSH2004190	Title	Ms
First Name(s)	Jone		
Surname/Family Name	Garcia Lurgain		
Thesis Title	An ecological exploration of the barriers and facilitators to cervical cancer screening and HPV self-sampling acceptability among Moroccan and Pakistani women in Spain		
Primary Supervisor	Joanna Busza		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	[Redacted]		
When was the work published?	[Redacted]		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	[Redacted]		
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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	International Journal for Equity in Health
Please list the paper's authors in the intended authorship order:	Jone G. Lurgain ¹ , Hakima Ouaarab Essadek, Khadija Mellouki, Sumaira Malik Hameed, Andleed Sarif, Valentina Rangel-Sarmiento, Laia Bruni, Paula Peremiquel-Trillas

Stage of publication	Submitted
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SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I am the first author of this paper and I was responsible for study design and data collection, and I led on the analysis (with support from my supervisor Joanna Busza) and interpretation of the data. I was also responsible of the conception of the paper and wrote the first draft of the manuscript, received feedback from all co-authors and responded. I will lead on the manuscript submission to the journal, and I will be responsible for responding to all reviewer comments and resubmission of the paper.</p> <p>This manuscript will be published with creative common licence CC-BY</p>
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SECTION E

Student Signature	Jone G Lurgain
Date	24 June 2024

Supervisor Signature	Joanna Busza
Date	24 June 2024

7.2 Abstract

Background: Immigrant populations, especially women, continue facing challenges in accessing quality healthcare, particularly sexual and reproductive health services (SRH). Poor cultural competent health systems contribute to communication challenges between immigrant women and healthcare providers perpetuating health disparities. This exploratory study describes these communication barriers from the perspective of Moroccan and Pakistani immigrant women and healthcare providers within the Catalan health system and its implications to ensure an equitable provision of SRH services.

Methods: An exploratory-descriptive qualitative study was conducted in various municipalities of Barcelona with high concentration of immigrants. Eight focus groups ($N = 51$) and semi-structured interviews ($N = 22$) with Moroccan and Pakistani immigrant women were combined with key informant interviews ($N = 13$) with healthcare professionals. Thematic analysis and data triangulation were performed primarily using an inductive approach.

Results: Language barriers and cultural differences in health needs, expectations, care-seeking behaviours and understanding of quality healthcare provision hindered the ability of immigrant women and providers to interact effectively. Limited availability of intercultural mediators and inadequate cultural competence training opportunities for health staff were also identified. Findings suggest a lack of minority representation in the Catalan health workforce and leadership roles.

Conclusion: This study reinforces the evidence of persistent inequities in accessing healthcare among immigrant populations by focusing on the cultural competence barriers of the Catalan health system in the provision and access to SRH services. The regularization of adequately trained intercultural mediators, quality training in cultural competence for health staff and a commitment to increase workforce diversity would contribute to improve intercultural communication between immigrant patients and providers. An urgent call to action in this direction is needed to ensure an equitable access to SRH services among immigrant women.

7.3 Research paper 3

Background

Despite efforts made over the last two decades, evidence of disparities between immigrants and non-immigrants in accessing healthcare services persist across Europe (Gil-Salmerón et al., 2021; Rechel et al., 2013; Norredam and Krasnik et al., 2011). Poor cultural competent health systems contribute to communication challenges between immigrant patients and healthcare professionals limiting an equitable access and use of healthcare services (Vange et al., 2023; Barrio-Ruiz et al., 2023). For instance, poor patient-provider communication can negatively affect the quality of care, satisfaction, treatment compliance and, ultimately, patients' health outcomes (Al Shamsi et al., 2020; Ahmed et al., 2017). Communication is especially challenging in the provision of sexual and reproductive health (SRH) services due to the sensitivity of the topic. In this context, communication barriers undermine immigrant women's right to benefit from SRH care and to make informed decisions concerning their health (Barrio-Ruiz et al., 2023; Sawadogo et al., 2023). Addressing these communication barriers between immigrant patients and healthcare professionals is, therefore, imperative and urgent.

Intercultural communication in healthcare is the interaction between healthcare professionals and patients of different cultural groups (international, interfaith, interethnic, interracial) to reach an understanding, build a shared reality and establish a satisfactory relationship (Jackson, 2016; Martin, 2015). It requires verbal and non-verbal communication skills, cultural sensitivity, constructive emotional expression, cultural knowledge and adaptability (Paternotte et al., 2015). Competence in intercultural communication is also considered a self-reflective practice that can be inculcated, trained and achieved (Lakra, Bhayani and Sulaiman, 2023). Healthcare professionals' intercultural communication skills help to provide a comfortable environment for discussion and involvement of patients in the decision-making process, as well as for trust (Belasen and Belasen, 2018), resulting ultimately in better health outcomes (Jenstad et al., 2024). Competence in intercultural communication is, therefore, critical to ensuring quality healthcare delivery for immigrant populations and reduce health inequities.

The concept of cultural competence goes beyond healthcare providers' intercultural communication skills and also involves the ability of organizations to effectively deliver healthcare services that meet the social, cultural and linguistic needs of patients (Betancourt, Green and Carrillo, 2003), which is particularly crucial when serving immigrant populations (WHO, 2020; Pocock et al., 2020; Truong, Paradies and Priest, 2014; Eken et al., 2021). The deployment of intercultural mediators -whose role is to reduce linguistic but also cultural barriers between patients and providers (Verrept, 201)- and the provision of training for health staff are common cultural competence interventions adopted by health

systems to improve accessibility and effectiveness of health services for immigrant populations (Pocock et al., 2020; Verrept, 2019; Origlia-Ikhillor et al., 2019; Handtke, Schilgen and Mösko, 2019; Jongen, McCalman and Bainbridge, 2018). Studies have shown that intercultural mediators can increase the uptake of preventive measures (Jacobs et al., 2001) and patient and provider satisfaction (Heath, Hvass and Wejse, 2023; Soh et al., 2022), reduce adverse events (Flores, 2005), as well as rates of unnecessary examinations, hospitalisations and costs (Flores, 2005; Hampers and McNulty, 2002). Despite these positive effects, intercultural mediator services are scarce in many European countries (Jaeger et al., 2019). Additionally, cultural competence training is seldom included in the healthcare professionals' curriculum, and they consequently bear the responsibility of filling the gap and developing their own cross-cultural competences (Shepherd et al., 2019; Hudelson, Perron and Perneger, 2011; Blue, Charles and Fleming, 2009; Kripalani et al., 2006; Juckett, 2005).

In Spain, significant immigration flows began at the turn of the millennium when the non-native population doubled in just one decade, a growing tendency which has continued until now (INE, 2024; Ronda-Pérez et al., 2014). Catalonia was one of the regions that witnessed the largest influx of immigrants and, currently, its foreign population reaches 1.2 million (16.3% of the Catalan population) (IDESCAT, 2024). The largest non-EU majority groups, excluding immigrants from Latin America, come from Morocco (18.5% of the migrant population), China (4.9%) and Pakistan (4.3%) (IDESCAT, 2024), where most citizens' first language is neither Spanish or Catalan, and cultural differences are notable with respect to the host country (Hofstede, 2024).

Up to date, a very few studies have addressed cultural competence barriers in the provision of SRH services in the Spanish and Catalan contexts (Ramos-Roure et al., 2021; Plaza del Pino, Soriano and Higginbottom, 2013). Therefore, this study aims to fill this gap by describing the communication challenges between immigrant patients and providers in the context of the Catalan health system. Using the case of Moroccan and Pakistani immigrant women, the study explores the potential impact of these barriers to access SRH services and potential strategies to improve the Catalan health system's cultural competence. The perspectives of immigrant women and healthcare providers are presented together in a constructive way and recommendations are provided for policy makers' and practitioners' consideration.

Methods

Study design

An exploratory-descriptive qualitative research design (Hunter, McCallum and Howes, 2018) was used to explore cultural competence barriers in the provision of care within the primary care SRH centres (referred to as ASSIR) in Barcelona province. We focused on communication barriers between Moroccan and Pakistani immigrant women and healthcare providers in accessing SRH services, and particularly cervical cancer screening since the study was embedded in a larger organised population-based cervical cancer screening implementation program in Catalonia, Spain. This qualitative design enabled us to gain an in-depth understanding of what happens before, during and after the medical encounter and reasons for communication barriers as perceived by Moroccan and Pakistani women and healthcare providers.

Sampling and recruitment strategies

Immigrant women and healthcare providers were selected using maximum variability sampling: convenience, purposive and snowball sampling techniques were combined based on age, length of stay in Spain, educational background or healthcare role. Inclusion criteria for immigrant women were determined by their country of origin (Morocco and Pakistan), age at migration (16 years or older, thus not exposed to the public Spanish education system) and their eligibility to the cervical cancer screening program in Catalonia (aged 25 or turning 25 in the year of the study, up to 65 and having a cervix). The main inclusion criteria for healthcare professionals were that they needed to be working actively in the primary care SRH centres and interacting directly with these two groups of immigrants. No exclusion criteria were established for healthcare professionals, but we ensured that providers reported at least ten consultations per week with immigrant patients from Morocco and/or Pakistan. Half of healthcare professionals reported that at least 50% of their patients were immigrants. The final sample size was determined when data saturation was achieved, indicating that additional interviews no longer provided new insights into the key dimension of the study.

We recruited Moroccan and Pakistani participants in neighbourhoods of Barcelona city, Sant Adrià del Besòs, Terrassa and L'Hospitalet de Llobregat. These were chosen because they represent different health districts, have a high proportion of Moroccan and Pakistani immigrants and include urban and semi-urban residential areas.

We recruited a wide range of healthcare professionals, such as community health workers, nurses, midwives, gynaecologists, all of whom worked in primary care SRH centres located in the same areas where most women participants were recruited. An intercultural mediator was also included, as these professionals greatly contribute in the provision of care for immigrants.

Data collection

Study fieldwork was performed between July and January 2023. A total of 8 focus group discussions (FGDs) (4 [all in Darija] with 24 participants from Morocco and 4 [all in Urdu] with 27 participants from Pakistan), 22 semi-structured interviews (SSIs) (12 [7 in Darija and 5 in Spanish] with Moroccan and 10 [5 in Urdu, 1 in Punjabi and 4 in Spanish] with Pakistani women) and 13 key informant interviews (KIIs) [all in Spanish] with healthcare providers were conducted.

Topic guides for FGDs and SSIs with immigrant women were designed based on a literature review on barriers and facilitators to cervical cancer screening among immigrant populations conducted for a broader study mentioned above. Questions covered individual (i.e. lack of language skills), interpersonal (i.e. social influences and cultural norms) and health system (i.e. interpreting and translation services) level factors. FGDs were moderated by a nurse (HOE) and a community health worker (SMH) with the same cultural and linguistic background as participants, and the first author (JGL) and two research assistants (RAs) (KM and AS), second-generation immigrant university students, conducted the SSIs. FGDs were conducted in community and religious centres (e.g. mosques) and the interviews were conducted in places chosen by the participants (e.g. women's and interviewers' home, religious centres). Further details of the data collection process have been reported elsewhere (Lurgain et al., 2024).

Interviews with healthcare providers explored their views and experiences providing SRH services, and specifically cervical cancer screening, to immigrant women. The overall goal was to understand how these women access healthcare, their preventive health practices, and their engagement with SRH services from the perspective of those who directly work with immigrant populations. These KIIs with healthcare providers also aimed to identify potential cultural and religious barriers and discuss strategies to increase participation in cervical cancer screening programmes, including the potential acceptance of HPV self-sampling. The first author (JGL) carried out all the interviews with healthcare professionals. These took place in the providers' workplace, except three interviews which were conducted either at the interviewee's home ($N = 2$) or via phone ($N = 1$).

Data analysis

The RAs (KM and AS) transcribed women's audio recordings from Darija and Urdu directly into Spanish and English, respectively, with minor editing to improve readability. The first author (JGL) and a co-author (VRS, physician and public health student) transcribed healthcare providers' audio recordings into Spanish. We conducted a social constructionist thematic analysis (Braun and Clarke, 2006; Vaismoradi, Turunen and Bondas, 2013) using mainly an inductive (data-driven) approach, although we used some predetermined themes (deductive approach), such as language limitations. We developed preliminary codebooks, using pen-and-paper and Microsoft Office Word and Excel, in which themes and sub-themes were defined (Auerbach and Silverstein, 2003). JGL, VRS and PPT independently coded two transcripts from each type of dataset (FGDs and SSIs with immigrant women and KIIs with healthcare professionals) and after discussion, agreement on a codebook (one for immigrant women and one for healthcare providers) was reached. Transcripts were uploaded into the qualitative data management software ATLAS.ti 23 (Scientific Software Development GmbH, 2023) and the first author (JGL) developed the final codebooks incorporating new emerging codes or removing those which were not relevant. For validation of themes and sub-themes, the above researchers coded additional transcripts using the final codebooks. FGD and SSI data obtained from Moroccan and Pakistani women and data from the KII with the healthcare providers were then analysed separately with the assistance of ATLAS.ti 23.

After coding and analysing the two datasets from immigrant women and healthcare providers separately, a data triangulation process was performed following a 'complementary' approach: searching to describe a problem (e.g. cultural competence barriers to access SRH services) from different perspectives (O'Cathain, Murphy and Nicholl, 2010). Specifically, the triangulation process was guided by the cultural competence framework proposed by Betancourt, Green and Carrillo (2003), which allowed us for an overall interpretation of the findings. This framework identifies three major levels of healthcare at which cultural competence barriers occur that contribute to health disparities: (1) clinical barriers, which occur when sociocultural differences in the interaction between patients and providers are not fully accepted, appreciated, explored or understood; (2) structural barriers, which refer to the availability of trained intercultural mediator services or culturally/linguistically appropriate health education materials, and (3) organizational barriers, which pertain to the representation of racial/ethnic minorities in the healthcare workforce and leadership roles. A summary of the main themes and sub-themes is provided in Table 15.

Table 15 Summary of cultural competence barriers in the provision of SRH services in the Catalan health system.

THEMES	SUB-THEMES
Theme 1:	
Clinical barriers	<ul style="list-style-type: none"> • Lack of language skills • Perceived discriminatory attitudes • Time pressure in the provision of care • Cultural taboos (e.g. offering certain SRH services) • Limited patient informed consent and confidentiality
Theme 2	
Structural barriers	<ul style="list-style-type: none"> • Limited availability of intercultural mediators • Limited and underused translation services and materials • Lack of adequate cultural competence training for health staff
Theme 3	
Organisational barriers	<ul style="list-style-type: none"> • Low minority representation in the healthcare workforce (e.g. nurses) • Low minority representation in leadership roles

**Note that some of the clinical and structural barriers could also be organisational.*

Ethical considerations

The study was approved by the Research Ethics Committees of the London School of Hygiene & Tropical Medicine (26186), Bellvitge University Hospital (PR 140/22) and Vall d’Hebron University Hospital (PR(AG)317/2022). Each participant was provided with comprehensive information about the study and gave written informed consent prior to data collection. Immigrant women were compensated with a public transportation 10-trip pass to ensure that participation did not impose a financial burden on them (transport to FGDs’ and SSIs’ locations) and to acknowledge their contribution to the research. Healthcare professionals did not receive any compensation.

Results

Participants' socio-demographic characteristics

The Moroccan and Pakistani participants' ages ranged from 24 to 65 years. The majority (82.2%) were married and nearly all Pakistani women (97.3%) had children, compared with 77.8% of Moroccan women. The primary reason for migration was family reunification. Despite most women (80.0%) of both groups having lived in Catalonia for over 5 years, up to 63% of them (52.8% Moroccan and 73% Pakistani) reported needing a translator during medical visits. A similar percentage was found among women who had arrived in the country (less than 5 years ago). Moroccan women were more likely to speak Spanish or Catalan at home than Pakistani women (33% vs. 5%). A total of 72.6% of participants reported having been screened for cervical cancer at least once in their lifetime. Women's detailed socio-demographic information can be found in Table 16.

Healthcare providers' ages ranged from 29 to 59 years. All of them were female, except for a gynaecologist and a community health worker. Furthermore, eight healthcare professionals were Spanish (mainly from Catalonia) and bilingual (Spanish/Catalan) and, five were originally from either Morocco or Pakistan and one of them also bilingual (Table 17).

Table 16 Women's socio-demographic characteristics by country of origin.

	Total participants		Morocco		Pakistan	
	N	(%)*	N	(%)*	N	(%)*
Participants¹	73	(100%)	36	(49.3%)	37	(50.7%)
Age. median (IQR)²	42	(35-48)	39	(33-46)	40	(34-47)
Age groups						
24-34 years	18	(24.7%)	7	(19.4%)	11	(29.7%)
35-44 years	28	(38.4%)	13	(36.1%)	15	(40.5%)
45-54 years	19	(26.0%)	10	(27.8%)	9	(24.3%)
55-65 years	8	(11.0%)	6	(16.7%)	2	(5.4%)
Level of studies						
No studies	9	(12.3%)	7	(19.4%)	2	(5.4%)
Primary school	15	(20.5%)	9	(25.0%)	6	(16.2%)
Secondary school	25	(34.2%)	14	(38.9%)	11	(29.7%)
Vocational training	3	(4.1%)	2	(5.6%)	1	(2.7%)
University	21	(28.8%)	4	(11.1%)	17	(45.9%)
Marital status						
Single	4	(5.5%)	4	(11.1%)	0	(0.0%)
Married	60	(82.2%)	26	(72.2%)	34	(91.9%)
Separated or divorced	7	(9.6%)	5	(13.9%)	2	(5.4%)
Widowed	2	(2.7%)	1	(2.8%)	1	(2.7%)
Children						
Yes	64	(87.7%)	28	(77.8%)	36	(97.3%)
Time since migration to Spain						
<2 years	7	(9.6%)	2	(5.6%)	5	(13.5%)
2-5 years	11	(15.1%)	8	(22.2%)	3	(8.1%)
6-10 years	19	(26.0%)	4	(11.1%)	15	(40.5%)
>10 years	36	(49.3%)	22	(61.1%)	14	(37.8%)
Reason of migration						
Economic	1	(1.4%)	1	(2.8%)	0	(0.0%)
Family reunification	62	(84.9%)	27	(75.0%)	35	(94.6%)
Tourist/student visa	7	(8.2%)	6	(16.7%)	1	(2.7%)
Not reported	3	(2.7%)	2	(5.6%)	1	(2.7%)
Languages most spoken at home³						
Spanish or Catalan ⁴	14	(19.2%)	12	(33.3%)	2	(5.4%)
Arabic (Darija)	31	(42.5%)	31	(86.1%)	0	(0.0%)
Urdu	33	(45.2%)	0	(0.0%)	33	(89.2%)
English	5	(6.8%)	1	(2.8%)	4	(10.8%)
French	3	(4.1%)	3	(8.3%)	0	(0.0%)
Other ⁵	8	(11.0%)	3	(8.3%)	5	(13.5%)
Spanish language skills						
I always need a translator	20	(27.4%)	8	(22.2%)	12	(32.4%)
Most of the times I need a translator	8	(11.0%)	3	(8.3%)	5	(13.5%)
Sometimes I need a translator	11	(15.1%)	6	(16.7%)	5	(13.5%)

I do not need translator at all	27	(37.0%)	17	(47.2%)	10	(27.0%)
Public health insurance						
Yes	68	(93.2%)	34	(94.4%)	34	(91.9%)
No	2	(2.7%)	0	(0.0%)	2	(5.4%)
Cervical cancer screening status						
I don't know what CC screening is	4	(19.2%)	0	(0.0%)	4	(10.8%)
Never screened	14	(19.2%)	7	(19.4%)	7	(18.9%)
Ever screened	53	(72.6%)	27	(75.0%)	26	(70.3%)

CC: cervical cancer; IQR: interquartile range

* Column percentages; percentages may not add up to 100% due to missing values.

¹ Percentages correspond to row percentages.

² Median and IQR were used as variable age was not normally distributed.

³ Percentages were calculated among the total participants for each language, as multiple options could be selected in the socio-demographic questionnaire.

⁴ Twelve women spoke Spanish at home. One woman reported only Catalan and another reported Catalan and Spanish as languages most spoken at home.

⁵ Includes Riffian (N=3, Moroccan women) and Kashmiri and Punjabi (N=1 and N=4, respectively, among Pakistani women).

Table 17 Characteristics of healthcare providers.

Key informant interviews (N=13)	Sex	Age	Country of origin	Occupation	Healthcare experience (years)
KI01	F	46	Morocco	Coordinator nurse	18
KI02	F	55	Spain	Midwife / Management role	30
KI03	F	33	Spain	Gynaecologist	7
KI04	F	45	Pakistan	Community Health Agent	8
KI05	F	59	Spain	Midwife	35
KI06	F	31	Spain	General Practitioner	5
KI07	M	49	Morocco	Community Health worker	10
KI08	F	32	Morocco	Intercultural mediator	9
KI09	M	36	Spain	Gynaecologist	10
KI10	F	30	Spain	Gynaecologist	4.5
KI11	F	29	Spain	Midwife	6
KI12	F	50	Spain	Midwife	26
KI13	F	29	Spain	Midwife	5

Cultural competence barriers

Qualitative findings from the FGDs and SSIs with immigrant women, as well as from the interviews with healthcare professionals are presented below and organised by each of the cultural competence barriers identified in the framework proposed by Betancourt, Green and Carrillo (2003).

1) Clinical barriers

Lack of language skills

We identified the inability to understand and speak either of the two official languages in Catalonia (Spanish/Catalan) as a barrier among Moroccan and Pakistani women regardless of their length of stay in the country. According to healthcare providers' perceptions, language barriers appeared more prevalent among Pakistani than Moroccan women.

Women from both countries often depended on the availability of their husbands, family members and friends to arrange appointments or to receive information. For instance, when their male partners could not accompany them, some women preferred to skip or postpone medical appointments until someone else was available. Whereas Pakistani women tended to visit the doctor with their husbands, Moroccan participants counted also on friends and even on other compatriots they met while waiting in the primary care centre for appointments.

“Many (Pakistani) women don't speak Spanish properly and they depend on their husbands' schedules to go to the doctor, and husbands work the whole day from Monday to Friday, so that's why women don't want to come” PC01 (Pakistani woman).

“I prefer to go to the doctor with someone who I know to help me with translation. I think I'm more comfortable. In the past my neighbour used to come with me” MC06 (Moroccan woman).

Whilst the support of the husband and other family members and friends seemed to attenuate the language barriers of women, this did not guarantee that they received accurate information about SRH services. Healthcare providers reported inadequate and incomplete translations by male partners and family members:

“Sometimes I see the husband explaining her wife what the doctor is saying, but not all, some just say a few things because they think the wife doesn’t need to know everything” KI04 (Pakistani community health worker).

“The first and most important thing is to make sure that women understand the information we provide, because we often give them the information through a third party [referring to the husband] who is not transmitting the information properly. It’s crucial to have a mediator or a person committed who can explain all of this, otherwise women won’t come to get screened” KI05 (female midwife).

Immigrant women and healthcare providers mentioned having personal strategies to overcome language barriers. Some women managed to communicate with providers using body language, through mobile phone conversations with family members or through paper notes, as this provider explained:

“They usually come with their own resources, like a mobile phone and someone on the other side of the phone line who does the translation, or a friend, or a neighbour... and sometimes they bring me a paper with the health issues or questions written by their partner (in Spanish) and I respond to them by hand on the same paper. I also explain to them that they need to come with a person who can translate, otherwise it’s very complicated for her to understand the treatment” KI12 (female midwife).

Body language, visual materials (e.g. pictograms), physical objects (e.g. plastic uterus), translated forms and Google Translator were resources used by midwives and gynaecologists to overcome language barriers:

“We manage with our body language; it’s true that using gestures, we and Moroccan women understand each other quite well, but non-verbal communication with Pakistani women is more difficult, because their body language, gestures are different to ours. I’m always afraid of doing a gesture that can appear offensive” KI02 (female midwife).

“We used to have some pictograms in different languages, but what I usually do is to give the information with drawings and sometimes with images as they help them to visualize a little bit what and where is the health issue” KI03 (female gynaecologist).

They also emphasized the importance of expressing empathy and building rapport with immigrant patients through eye contact and using some words in their local languages to improve

communication, as this female midwife explained: *“I have learned a couple of words in Arabic and I usually use them with Maghrebi women. They can see that I make efforts to facilitate communication and I create some empathy”* KI05 (female midwife).

The use of ‘third’ languages, such as English and French, was also mentioned by women and healthcare providers: *“I speak a little French, sometimes I ask Moroccan patients if they speak French, if they say ‘yes’, then we manage in French”* KI09 (male gynaecologist).

Perceived discriminatory attitudes

While immigrant women considered the Catalan health service to be good overall, even better than in their own countries, and healthcare providers to be “caring”, some women felt they did not receive the care they expected. Several participants reported a lack of empathy and unhelpful attitudes from the health staff, especially clinic receptionists, but also some healthcare providers. Women from both Moroccan and Pakistani origin reported feelings that health staff were racist and held discriminatory attitudes against them when they could not communicate properly in Catalan or Spanish, for instance, to book a medical appointment. This deterred some women from seeking healthcare services in Catalonia and instead, seeking care in their own countries:

“A few years ago, I couldn’t speak Spanish and I couldn’t find anyone who could accompany me to the midwife consultation. My husband worked in Portugal. Perhaps it was my responsibility to bring someone and be able to answer her questions... She spoke to me very aggressively. I can’t forget it” MG202 (Moroccan woman).

“Generally, they [healthcare providers] are kind, but there are receptionists in the health centres who don’t have any sensitivity when they attend a person who can’t speak properly in Spanish or Catalan. Instead of being empathetic and try to communicate or ask for help, they just ask ‘what are you saying?’, then, this person won’t come back. This is what happens with Pakistani women, they prefer to stay at home or wait to go to the gynaecologist in their country and pay, rather than face these unpleasant situations. Honestly, we prefer to pay [back home] and avoid taking an appointment here” PC05 (Pakistani woman).

Immigrant women also reported negative and discriminatory attitudes from healthcare providers, especially clinic receptionists, when they requested or expressed their preference for a female professional to undertake gynaecology examinations, deterring them from requesting a same sex provider in the Catalan health system:

“There is a Moroccan woman in my neighbourhood who requested a female doctor in her surgery and up to now she has been having troubles just because she wanted a female doctor (...) Sometimes the receptionists in the health centre don’t like that an immigrant woman requests a female doctor...they think she needs to accept what is available, that’s it, they think that immigrants do not have rights and can’t demand anything” MC01 (Moroccan woman).

“I had an experience here, a woman who recently came from Pakistan, she requested a female doctor, and the receptionist started to argue and say: ‘that’s the problem with you Pakistanis’ and then the woman didn’t get an appointment until three months later and the scan was in another hospital far from there and the husband asked to get the appointment in their health centre but the receptionist ignored it” PG203 (Pakistani woman).

We observed that lack of culturally sensitive policies or clear guidelines to address cultural conflicts led to some confusion concerning the right of immigrant women to request a healthcare professional of the same sex. Most providers interviewed understood Moroccan and Pakistani women’s preferences for female doctors and stated that they should have the right to request it. However, two gynaecologists raised concerns that choosing the sex of the health professional would contradict the gender equity and non-discrimination policies of the Catalan health system:

“You have the right to have a healthcare provider, to be attended, but you can’t choose whether the doctor is white or black, or whether the doctor is female or male, because it’s considered discriminatory. In the private health system, yes, you can choose whatever you want, but in the public health system, not” KI09 (male gynaecologist).

“They can’t officially request a female doctor just like you can’t request a white gynae or a heterosexual gynae ... It’d bother me if someone doesn’t want me to visit her just because I’m a woman. I know that there is a cultural barrier, but it annoys me that a professional can be judged because of his/her gender (...) Obviously, if the woman has suffered a sexual aggression, all of us would be empathetic [to her preference for a female provider]” KI10 (female gynaecologist).

Time pressure

Even when immigrant women possessed basic or everyday language capacity, some felt they were not being listened to properly as health providers did not give them sufficient time to explain themselves:

“Despite my broken Spanish, I try to explain the doctor my problems in detail, but she always cuts me off and doesn’t give me enough time to express myself. It’s like they work under lot of pressure, and since they have lots of patients, they attend you quickly” MC11 (Moroccan woman).

Healthcare providers confirmed this impression, explaining they have limited time allocated for each patient. Time pressure was even stronger when seeing immigrant patients with language difficulties, low literacy and lack of knowledge of the Catalan health system. This led providers to feel more overloaded and to express feelings of frustration and exhaustion:

“These visits are difficult and require more time... The time factor is like a sword stuck in your back. Sometimes you need to spend more time with these women to make sure they understand why we are doing these tests [cervical cancer screening tests]. (...) After so many years, I’m at a point where I feel exhausted (.) I’m constantly gesticulating to try to reach and communicate with these women; it’s exhausting” KI05 (female midwife)

“Sometimes they don’t understand the treatment, some of them don’t know how to navigate the health system or how to get the public health insurance (...) Some have low education and many times they come with medical consultations, basic issues, such as a headache, that other people wouldn’t be worried about [meaning additional burden]” KI11 (female midwife).

Cultural taboos

We identified cultural differences between women and healthcare providers’ beliefs and perceptions regarding the use of certain SRH services and the context in which they would discuss them. Addressing women’s health issues, such as menstruation, in front of male relatives (e.g. husbands, sons) and offering specific SRH services, such as contraception and pregnancy termination services, could be considered offensive or against women’s cultural and religious practices, while for healthcare providers these were common issues addressed with their patients. Cultural differences were also identified regarding certain health examinations, such as cervical cancer screening, at specific times, for example, during Ramadan. A midwife also referred to the difficulties that husbands sometimes found when explaining certain women’s issues:

“If you are pregnant, our religion doesn’t allow us to get abortion, you cannot ask the doctor for abortion services... you are pregnant and you need to accept it” MC05 (Moroccan woman).

“A woman came with her 9 years old son to help her to translate. I asked the child to ask his mum the date of her last menstruation and the child told me that he couldn’t ask this kind of question to his mum... They are difficult situations because culturally, women don’t talk about these topics in front of specific family members [referring to males and children]. For me, it was an important barrier because I need this information” KI02 (female midwife).

“For example, I had a patient who rejected to be examined because it was Ramadan and she told me it was not allowed during Ramadan. She came three weeks later for the examination” KI03 (female gynaecologist).

“The other day a man came to my consult with his wife who had a vaginal problem and he didn’t know how to express the problem. He told me that she had pain “in the secret”, and I couldn’t understand what ‘the secret’ was. He couldn’t explain the problem in a different way. In some cultures, men find it difficult to speak with a woman about these issues” KI11 (female midwife).

Healthcare professionals also mentioned difficulties in addressing topics related to sexual health and genitalia. In this, they distinguished between first-generation and second-generation immigrants, perceiving the latter to be more aware of their bodies and willing to ask questions about sexual health, whereas the former were more ‘detached’ from their own bodies and had lower literacy about their own anatomy. This led some healthcare providers to provide basic information about certain tests:

“Many times we cannot explain much more because otherwise we had to start giving them a class of anatomy in fifteen minutes (...) But it’s true that sometimes I simplify a little bit when it comes to cervical cancer prevention and we just say that we’ll check that ‘everything is ok’” KI11 (female midwife).

Informed consent and confidentiality

While immigrant women considered their husbands and other relatives as the most important social support in the host country, the health professionals sometimes found them more of an obstacle during health consultation. For instance, some professionals expressed concern about whether immigrant women made informed decisions about their SRH: *“Many times I have the impression that it’s the husband who makes the decisions for them. For example, I ask him to translate and he just makes a very short translation and then he basically orders her to take off her underwear for the vaginal examination. But I need her to understand me, I need him to translate well and her to make the decision” KI02 (female midwife).*

Despite this informed consent issue, a midwife emphasized the importance of establishing a good relationship with husbands due to their role as decision-makers. However, she pointed that culturally this is a challenging goal:

“...It’s really hard, but it’s like this. If you have some empathy with the husband, this woman will come back, because we can’t build rapport with some women, they don’t speak any word in Spanish” KI05 (female midwife).

Similarly, healthcare professionals felt that the presence of a family member reduces confidentiality and provider-patient privacy, something that is a foundation of how healthcare professionals understand quality care. For instance, the presence of relatives prevented providers from screening Moroccan and Pakistani women for highly sensitive issues, such as domestic violence or sexually transmitted infections (STIs): *“Of course, there are some specific issues we can’t address. For example, we have a questionnaire to screen all pregnant women for domestic violence. If her partner comes always to the visit with her, we can’t address this. It’s true that you can observe the relationship between them, behaviours during the visit, etc., but it’s difficult” KI11 (female midwife).*

Healthcare providers also reported challenges in ensuring confidentiality when they need to communicate a test result or give an appointment by phone to a woman with language difficulties, and a midwife expressed other ethical challenges they face when immigrant women go to the health centre accompanied by their underaged children to help them with translation. In these circumstances, she explained that professionals skip some explanations regarding the genitals and vaginal examination and give the patient only basic information. Gynaecologists and midwives narrated their strategies to ensure users’ privacy and confidentiality, but all of them agreed that the availability of intercultural mediators would be the most effective support to ensure confidentiality and health informed decisions:

“When a mediator is available we can ask the partner to get out or the woman can come alone another day and then it’s easier to address these issues [e.g. STIs, vaginal problems] with the presence of a mediator” KI11 (female midwife).

2) Structural barriers

Limited availability of trained intercultural mediators

We found disparities in the provision of intercultural mediators across the Catalan health system. Whilst the primary care centres in those neighbourhoods of Barcelona city with the highest concentration of immigrants, such as Raval and Besòs, offered intercultural mediator services in various languages (e.g. Arabic, Urdu, Chinese), in other municipalities with similar volume of immigrants, such as Terrassa and L'Hospitalet de Llobregat, these services were very limited or even non-existent:

“The availability of intercultural mediators is very important for us. Ten years ago we had the possibility of these services, it was a project funded by the Caixa Foundation, they trained mediators from different cultures, and then unfortunately this service disappeared in almost all primary healthcare centres” KI02 (female midwife).

Since mediator services were scarce, informal interpreter services were voluntarily provided by health staff of Moroccan and Pakistani origin, as this gynaecologist explained: *“In the ASSIR unit [primary care SRH centre] we have two auxiliary nurses, one from Pakistan and one from Morocco. They are usually working in the maternity ward, but sometimes they go to the primary care units to help with translations, but it's not their role, they are auxiliary nurses...” KI09 (male gynaecologist).*

We also found that the intercultural mediators working currently in Barcelona are not integrated into the health system. Most of these professionals received training in intercultural mediation in the past and currently they are hired by outsourced companies and work in challenging conditions, as some providers confirmed and a mediator explained: *“The company offers cleaning and security services, and now intercultural mediation services. We are hired by this company, if we would be directly hired by CatSalud [the Catalan Service of Health, the public institution leading health planning and management in Catalonia] our work conditions and salaries would be better” KI08 (female intercultural mediator).*

Despite the scarcity of intercultural mediators and lack of integration of these professionals within the health system, interviewed healthcare providers agreed that intercultural mediators play an important role in ensuring effective communication and provision of quality care to immigrant patients who lack language skills, especially in the paediatric and primary care SRH centres. They advocated for the regulation of the cost of these services in the Catalan health system and emphasized the importance of equipping these professionals with adequate intercultural mediation training to minimise potential

conflicts, as healthcare providers pointed out that these professionals are not mere interpreters, but health mediators with specific training in cultural skills:

“The difficulty I found in the beginning is that the Moroccan interpreter [referring to intercultural mediators] translated according to her beliefs, which was a handicap. For example, a young girl with an unwanted pregnancy came and I asked whether she wanted to continue with the pregnancy or interrupt it, and the Moroccan interpreter ‘jumped’ into the conversation with a smile telling me ‘we [Muslims] don’t interrupt pregnancies’. I needed to tell her that she only had to translate without judgements or giving opinions. After some time and with more experience, we solved this situation. It’s important to train the interpreters [referring to intercultural mediators] and make sure they understand their role” KI12 (female midwife).

One healthcare professional added that even when the mediation services are needed and available, these must be offered as an option, referring to the reluctance expressed by some immigrant women to use these services due to a lack of trust. In this sense, a midwife concluded that greater efforts must be made to explain the role of the intercultural mediators and facilitate trustee relationships between these and immigrant patients.

Finally, a midwife highlighted the importance of taking into consideration the gender of the mediators, at least in the primary care SRH centres: *“The women didn’t want him [referring to a male intercultural mediator] to be in the medical consultation, because he was a man. They felt uncomfortable with a male interpreter and they were worried that he could know someone in their community” KI02 (female midwife).*

Limited and underused translation services

In addition to this insufficient number of intercultural mediators, we found an underutilisation of the available telephone translation service (061 Salut Respon) by providers. They expressed mixed opinions about this service’s effectiveness. Some considered it a good alternative if mediators were not available, but most admitted to not using this service because it was too slow for the limited time assigned per patient and suboptimal to address language and cultural problems. A few healthcare professionals were even unaware of its existence.

“They put you in contact with a health translator and then you have the conversation with the woman and the interpreter gives you simultaneous translation via phone. I think it’s helpful and ensures anonymity” KI02 (female midwife).

“It’s the slowest thing in the world! I have 15 minutes per visit! It takes ages until they find an available translator, you can’t wait for this. We need more resources, like mediators. I manage with materials and forms translated into various languages” KI09 (male gynaecologist).

The availability of culturally and linguistically appropriate information and education materials seemed also scarce. Healthcare professionals noted that the webpage from the Department of Health (Canal Salut), is translated into English and French in addition to the official languages in Catalonia. They explained that they usually used information and education materials (e.g. questionnaires, forms, health prevention flyers) translated into different languages, although some providers mentioned a lack of translations in Urdu, for instance.

Lack of adequate cultural competence training for health staff

The majority of the healthcare professionals interviewed had attended cultural competence training courses at some point in their careers. They found the courses helpful but inadequate, as they were often short, general and lacked interactive activities. Some providers strongly believed that formal and compulsory training on cultural competence should be integrated into the healthcare professionals’ curriculum. Currently, cultural competence training sessions are usually provided by community-based and non-governmental organisations, and lack institutionally funding, relying on the availability of private funds.

“I miss in our university medical studies this cross-cultural perspective, because the view is very ‘Western’ and we need to keep in mind that in other cultures people understand health and wellbeing in different ways. I think the experience working with these populations gives you the knowledge, you learn from immigrant patients about their habits, cultural beliefs, etc. Empathy and cultural sensitivity are the basics” KI06 (female general practitioner).

Some healthcare professionals also proposed training administrative staff, particularly receptionists, on migrants’ rights because *“not all health staff know the law and the bureaucratic circuits of the health system. There is confusion among the administrative staff and there are situations in which they may deny health services to immigrants because of lack of knowledge” KI06 (female general practitioner).*

3) Organizational barriers

Healthcare providers mentioned that an ideal solution to overcome cultural competence issues would be to have a more diverse health workforce, in this case, more Moroccan and Pakistani nurses, midwives and gynaecologists: *“We had a Chinese gynaecologist and at that time Chinese patients started to come to the clinics like never before”* KI02 (female midwife).

Immigrant women also welcomed the availability of more healthcare staff from their own countries and they thought this would improve communication between immigrant patients and providers. A few Moroccan participants observed an increasing number of pharmacists, nurses, auxiliary nurses and doctors with Arabic language skills: *“He was a Syrian doctor and I liked it, he explained me in Arabic and even though my local language is Darija, I understood him”* MG205 (Moroccan woman). However, in the leadership roles the minority representation seemed low.

Discussion

To the best of our knowledge, this is the first study describing cultural competence barriers in the context of the primary care SRH centres in Catalonia, Spain, from the perspective of Moroccan and Pakistani immigrant women and healthcare providers. First, at clinical level, the results indicate that lack of command of the local languages (Spanish and Catalan) and cultural differences in health needs, expectations, care-seeking behaviours and understanding of the provision of quality care hindered the ability of immigrant women and care providers to interact effectively. Second, at structural level, we identified limited availability of intercultural mediator services and translation materials, and inadequate cultural competence trainings available for healthcare staff. Finally, at organisational level, results suggest low minority representation in the health workforce and leadership roles of the Catalan health system.

Lack of knowledge of the host country’s official languages is one of the dominant barriers to obtain accurate health information, and access and use of quality healthcare services (Barrio-Ruiz et al., 2023; Zhao, 2021; Origlia-Ikhilior et al., 2019). Although language barriers commonly affect first-generation immigrants during the resettlement period (Pandey et al., 2021), our research found that regardless the length of stay in the host country many Moroccan and Pakistani women struggled to communicate with healthcare staff, for instance, to book gynaecological appointments -women often depended on the availability of informal translation services from family or friends-, as well as to convey their health issues and understand healthcare providers’ explanations. These language limitations may have important implications, such as delayed access to timely healthcare, suboptimal

care, increased risk of adverse events and dissatisfaction with care received and poor health outcomes, as reported in previous studies with immigrant patients in Canada (Pandey et al., 2021; De Moissac and Bowen, 2019).

The contested issue about the sex of the healthcare provider, especially providing SRH services, has been extensively addressed in the literature (Aubrey et al., 2017). In our study, both immigrant women and healthcare providers reported feelings of perceived discrimination when requesting a female healthcare professional or for being rejected on the basis of gender, respectively, which suggest a lack of culturally sensitive policies to address this type of cultural ‘conflicts’. Guidelines are thus urgently needed to help healthcare providers manage cultural challenges, as other neighbouring countries with longer history of migration (e.g. United Kingdom) already have in place (British Government, 2017).

Feelings of perceived discrimination have been shown in previous research with immigrant women in Finland and Spain, where participants reported “unfriendly” attitudes and poor communication with healthcare staff (Pérez-Urdiales et al., 2019; Degni et al., 2013). In line with our study, in another research conducted in Switzerland, real or perceived discrimination was rarely mentioned by immigrant patients except in relation to experiences at the registration desk prior to clinical appointments (Schmidt et al., 2018).

Time pressure was also a relevant factor hindering communication between immigrant patients and healthcare providers. On the one hand, immigrant women reported not being given sufficient time to explain their health problems and, on the other hand, healthcare providers reported that low language skills often meant immigrant patients required longer consultation times and greater efforts to communicate with them. This, along with time constraints due to heavy patient loads, led providers to feeling frustrated and overworked, which was attributed by one gynaecologist to immigrants’ inappropriate use of healthcare services. This perception concerning immigrants’ use of the public healthcare services was also found in previous studies conducted in Catalonia with healthcare providers (Ramos-Roure et al., 2021; Terraza-Núñez et al., 2011). However, migrant health literature has demonstrated that immigrant populations’ medical service usage is not as frequent as perceived. For instance, a recent study found that immigrants tend to underuse maternal health services and have an increased risk of poor SRH outcomes (Alarcão et al., 2021).

The above findings demonstrate how the intersection of language barriers and lack of sufficient resources (e.g. personnel) hinder the communication between immigrant patients and healthcare professionals. Despite these challenges, we found that both immigrant women and healthcare professionals made efforts to understand each other. Non-verbal communication, such as body

language and pictograms, and the use of Google Translator were some personal strategies reported in this and previous studies conducted with migrants in Europe (Jaeger et al., 2019) and Southeast Asia (Pocock et al., 2020). However, while these efforts permitted basic understanding, they did not create the best conditions for trust and facilitation of good patient-provider relationships, as seen in a previous systematic review (Rocque and Leanza, 2015).

Consistent with previous research conducted with immigrant populations in Australia and the US (Napier-Raman et al., 2024; Hammoud, White and Fetters, 2005), this study confirmed that even when immigrant women started to master Spanish or Catalan languages, communication barriers persisted due to cultural differences. For instance, providers encountered challenges in addressing certain SRH issues (e.g. STI) and offering certain SRH services (e.g. pregnancy termination services), which immigrant patients might find offensive or conflicting with their religious beliefs.

Limitations to ensure confidentiality and obtained informed consent from immigrant women were other concerns raised by healthcare providers, who agreed that a fair deployment of intercultural mediators would help to address the above linguistic and cultural differences. However, we identified significant disparities in the deployment of intercultural mediators across the Barcelona province, with services predominantly available in primary care centres located in specific neighbourhoods within Barcelona city. This limited availability of mediator services aligns with findings from a recent systematic review assessing barriers and facilitators to access interpreter services in European health systems (Vange et al., 2023). Where free-of-charge intercultural mediation services exists (e.g. Germany, Croatia, Spain), the cost of these services, however, is not regulated either at national or European levels, leading to inconsistent provision of mediators and perpetuating patient-provider communication challenges, which in turn contributes to health disparities (Vange et al., 2023). Therefore, there is also an urgent need to expand and standardize the availability of trained intercultural mediator services within the Catalan health system and across other European regions, particularly in the primary care SRH centres.

As in other studies performed in Pakistan and Finland (Mustafa et al., 2023; Degni et al., 2012), in our research, healthcare providers expressed a certain amount of anxiety about their lack of cultural competence. In this sense, providers reported insufficient and inadequate cultural competence training opportunities in the Catalan context. Efforts should therefore be made to improve quality and access to this type of training not only for doctors, but also for nurses and other professional health staff, as suggested in another study conducted in Southern Spain with nurses and Moroccan patients (Plaza del Pino, Soriano and Higginbottom, 2013). The inclusion of cultural competence in the healthcare professionals' curriculum needs also to be considered, as previous research advocate (Lakra, Bhayani and Sulaiman, 2023).

Finally, field observation and key informant consultations suggested that the representation of minorities in the Catalan healthcare workforce is still low. Studies in the US have shown that diversity and inclusion can help organisations improve both patient care quality and financial results (Khuntia et al., 2022; Gomez and Bernet, 2019). Thus, this is another strategy to consider improving access and provision of quality SRH care to immigrant populations in Catalonia, Spain.

Based on our research evidence, the above cultural competence barriers at clinical, structural and organisational levels should be addressed in parallel with other health system deficiencies, such as saturation, excess of demand, insufficient time per patient (Suphanchaimat et al., 2015), in order to improve access to SRH services and reduce health inequities among immigrant populations. Additionally, we observed the need of developing further studies exploring and evaluating the effectiveness of new roles, such as community health agents, who not only provide intercultural mediation services, but also reach, promote and facilitate access to the health system among the most vulnerable immigrants within their communities.

This study has several methodological strengths and limitations. It is noteworthy to mention that the researchers' social position (e.g. gender, age, race, immigration status) and personal characteristics and experiences affect the research process (Berger, 2015). In this research, four authors have Moroccan or Pakistani origin, two authors were immigrant either in the Catalan/Spanish context or another foreign country and two authors were not immigrants and of Catalan origin. This diversity in backgrounds and experiences offered both insider- and outsider-perspectives on the topic, enhancing the richness in the research process and its outcomes. The insider-perspective enabled a deeper comprehension of participants' perceptions and interactions with the Catalan health system, allowing an accurate reflection in their viewpoints. Simultaneously, the outsider-perspectives from the non-immigrant authors in the Catalan/Spanish context provided a professional viewpoint that broadened the perspective beyond personal experiences. The inclusion of immigrant women's with and without language barriers and healthcare providers' perspectives is also an important strength of this study, as it facilitated an in-depth analysis where linguistic and cultural differences were confronted in a constructive way.

Regarding the study limitations, it is important to mention that the inclusion of only two national groups limits the generalizability of the findings to other immigrant experiences and cultural backgrounds, although it serves as a valuable case study. Additionally, the small sample size of healthcare professionals, who primarily work in areas with high concentration of immigrant populations, may not capture the perspectives from those working in areas where immigrants are less represented.

Conclusion

This study emphasizes significant cultural competence barriers within the Catalan health system that hinder immigrant patient-provider relationship, potentially increasing disparities in accessing SRH services in Catalonia, Spain. Addressing these barriers requires a fair deployment of intercultural mediators, clear guidelines to help manage cultural challenges, the formalization of cultural competence training for healthcare professionals, and a commitment to increase workforce diversity. These steps are crucial to mitigating the impact of language barriers and cultural differences on communication between immigrant patients and providers, thereby improving access to quality care. Health systems across Europe, including the Catalan health system, are urged to take a proactive role and implement on-the-ground actions aiming to improve cultural competence and ensure an equitable provision of quality care for immigrant populations.

Chapter 8 Moroccan and Pakistani women's knowledge and perceptions of cervical cancer screening and HPV self-sampling acceptability in Catalonia, Spain: a mixed-methods study

8.1 Introduction

In previous chapters, I analysed more broadly the determinants of Moroccan and Pakistani women's CC screening behaviours, such as the influence of their cultural and religious values on their preventive health behaviours, the role of women's personal networks and social norms shaping their health information and health behaviours, and the impact of the communication challenges between immigrant patients and healthcare providers on the access to and use of preventive services. In this chapter, I complete the analysis placing the focus on women's knowledge and perceptions of CC and HPV-based screening and examine whether or not HPV self-sampling would be an appropriate sample collection method for screening among these two groups of women. I also describe participants' recommendations for both the development of health promotion and educational interventions, and the implementation of HPV self-sampling in the Catalan context.

The data presented here were collected through a mixed-methods study. Qualitatively, I explored the extent to which women consider CC screening relevant in their communities, their screening preferences, and the challenges and opportunities that HPV self-sampling pose from the Moroccan and Pakistani women's perspectives. Quantitatively, I describe HPV self-sampling acceptability rates among these two particular groups of women, identify what type of women may benefit most or need more support to use HPV self-sampling, and capture their experience of the usability of two different devices (FLOQSwabs© and Evalyn©Brush).

Overall, this chapter responds to the fourth research question regarding the appropriateness of using HPV self-sampling to increase screening uptake and reduce inequities among Moroccan and Pakistani women and will specifically contribute to informing the design of a culturally and linguistically adapted intervention to raise awareness and prevent CC and HPV in these two immigrant communities.

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	LSH2004190	Title	Ms
First Name(s)	Jone		
Surname/Family Name	Garcia Lurgain		
Thesis Title	An ecological exploration of the barriers and facilitators to cervical cancer screening and HPV self-sampling acceptability among Moroccan and Pakistani women in Spain		
Primary Supervisor	Joanna Busza		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	[REDACTED]		
When was the work published?	[REDACTED]		
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Where is the work intended to be published?	BMC Health Services Research
Please list the paper's authors in the intended authorship order:	Jone G. Lurgain, Paula Peremiquel-Trillas, Hakima Ouaarab Essadek, Khadija Mellouki, Sumaira Malik Hameed, Andleed Sarif, Valentina Rangel-Sarmiento, Laia Bruni, Guy Harling and Clare Gilham

Stage of publication	Submitted
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SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I am the first author of this paper and I was responsible for study design and data collection, and I led on the analysis (with support from my supervisors Joanna Busza and Guy Harling, and the member of my Supervisory Committee, Claire Gilham, and Paula Peremiquel-Trillas from ICO) and interpretation of the data. I was also responsible of the conception of the paper and wrote the first draft of the manuscript, received feedback from all co-authors and responded. I will lead on the manuscript submission to the journal, and I will be responsible for responding to all reviewer comments and resubmission of the paper. This manuscript will be published with creative common licence CC-BY</p>
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SECTION E

Student Signature	Jone G Lurgain
Date	24 June 2024

Supervisor Signature	Joanna Busza
Date	24 June 2024

8.2 Abstract

Background. Disparities in cervical cancer (CC) screening participation persist, with lower rates among immigrant women from low-resource countries compared to European women. Evidence-based strategies to reach under-screened women are thus needed, such as adopting self-sampling for human papillomavirus (HPV) testing. Studies have demonstrated that women are receptive to HPV self-sampling. However, results may not be generalizable to all ethnic groups and settings. This is the first study in Spain assessing HPV self-sampling acceptability among immigrant populations. A mixed-methods study was used to explore Moroccan and Pakistani women's knowledge and perceptions concerning CC screening and their attitudes towards HPV self-sampling in Catalonia region.

Methods. Eight focus group discussions and twenty-two semi-structured interviews were conducted. After a short demonstration of two self-sampling devices, women were invited to try them at home and complete an acceptability survey per each device, including questions assessing screening preferences, perceived self-efficacy, trust in the test results and willingness to use the self-collection method again.

Results. Important barriers, such as lack of adequate information about CC screening, and misconceptions about HPV risk were identified. Overall, Moroccan and Pakistani women expressed a preference for clinician-based screening over self-sampling. Over half of the participants (56 %) agreed to try at least one self-sampling device. However, concerns about collecting the sample correctly and distrust in the test result were raised.

Conclusion. Increasing awareness and empowering Moroccan and Pakistani women with culturally appropriate information about the benefits of CC screening is the first step to successfully implementing HPV self-sampling among these populations. Concerns regarding self-efficacy also need to be addressed before implementing the newly organised population-based screening programme using HPV self-sampling in Catalonia, Spain. A peer-based approach using culturally appropriate materials is proposed to best inform, educate, foster confidence, and advocate for the uptake of HPV self-sampling among these two groups of women.

8.3 Research paper 4

Background

Human papillomavirus (HPV) is the most common sexually transmitted infection (STI): in Western countries, it is estimated that 80% of all sexually active individuals will contract an HPV infection through lifetime (Chesson et al., 2014). Despite its typical natural course and spontaneous elimination, a persistent infection can result in precancerous lesions, which may progress to cervical cancer after 5 to 20 years (Steenbergen et al., 2014; Trottier and Franco, 2006; Bosch et al., 2002). Globally, cervical cancer (CC) affects over 662,000 women and causes nearly 350,000 deaths every year (WHO, 2024).

CC can be effectively prevented through HPV vaccination and appropriate and timely screening. In Europe, well established population-based screening programmes have reduced mortality by 80% or more among screened women (Jansen et al., 2020) and HPV-based screening has been proved to be more effective than the traditional cytology in reducing precancerous cervical lesions incidence (Koliopoulos et al., 2017; Ronco et al., 2014). Yet disparities in screening participation persist, with lower rates documented among immigrant women from low-resource countries compared to native European women (Rosato et al., 2023; Hamdiui et al., 2022a; Hilverda, Fissers and van den Broek, 2021; Gele et al., 2017). For instance, earlier studies conducted in Spain indicate that Moroccan women rank among the immigrant groups with the lowest rates of cervical and breast cancer screening uptake (March et al., 2018; Pons-Vigués et al., 2012; Sanz-Barbero, Regidor and Galindo, 2011) and research in different high-income countries (HIC) also suggests that Pakistani women are an under-screened immigrant group (Qureshi et al., 2019; Lofters, Ng and Lobb, 2015; Szarewski, et al., 2009). Evidence-based strategies to reach not-screened or under-screened women are thus needed, such as the adoption of self-sampling for HPV testing (Di Gennaro et al., 2022; Serrano et al., 2022; Lozar et al., 2021; Yeh et al., 2019).

In Spain, CC screening is currently transitioning from opportunistic to population-based programmes. In April 2019, the publication of the Spanish Law (BOE, 2019) urged all regions to transition to organised population-based CC screening programmes and the implementation of the HPV test as the primary screening method. Several screening programmes, such as in the Netherlands (Dieleman et al., 2022) and Australia (Creagh et al., 2022), offer self-sampling as an alternative screening approach for women who do not wish to attend for clinician-based screening. The new population-based screening programme in Catalonia (GenCat – Department de Salut, 2023) will take a further step by designating HPV self-sampling as a primary method for sample collection for all women. HPV self-sampling will be offered to all women between the ages of 30 and 65. In addition to home-based HPV

self-sampling, the possibility to request a clinician-based screening will also be available for women who cannot collect the sample by themselves or who prefer this option. Since 2019, implementation pilot studies are taking place in different municipalities of Barcelona province to precede its broader implementation across Catalonia. Eligible women will be invited through short-message service (SMS) to collect self-sample devices in a near-by pharmacy. Pharmacies will also collect and deliver the samples to the laboratories. The results will be delivered through the Catalan digital personal health App (La Meva Salut) (ICO, 2024).

To date, studies strongly support HPV self-sampling, demonstrating comparable specificity and sensitivity to clinician-based samples using PCR technology (Gilbert, Sánchez-Contador and Artigues, 2023; Polman et al., 2019; Arbyn et al., 2018). However, assessing women's interest and willingness is crucial before implementing this sampling method for CC screening. Studies conducted mainly in Western countries have shown varying preferences towards this new approach over clinician-based (Narvaez et al., 2023; Drysdale et al., 2022; Nishimura et al., 2021; Morgan et al., 2019; Braz et al., 2017; Szarewski et al., 2009). Individual characteristics, such as age and education, influence women's screening preferences (Drysdale et al., 2022; Tisci et al., 2003). Also, cultural and health system determinants shape women's decisions around whether or not to get screened and which screening method they choose (Hamdiui et al., 2022a). HPV self-sampling has the potential to overcome known common barriers to conventional screening such as time constraints, embarrassment and discomfort (Dieleman et al., 2022), but self-sampling also poses its own challenges, such as the correct execution of the procedure and the trust in the result (Dieleman et al., 2022; Howard et al., 2009).

Most published literature on HPV self-sampling relies on data from quantitative questionnaires. According to these studies (Narvaez et al., 2023; Nishimura et al., 2021; Braz et al., 2017), women are generally receptive to HPV self-sampling. Yet results from HPV acceptability studies may not be generalizable to all ethnic groups and settings (Brewer et al., 2021). Quantitative surveys provide limited insights into barriers and facilitators to service uptake, which qualitative methods can explore in greater depth. Mixed-methods research studies are well-placed to capture both aspects (Patton, 2002). Research to date into HPV self-sampling in Spain has been limited to a few quantitative studies assessing acceptability among native women who attend regular CC screening (Ibáñez et al., 2023; Maldonado- Cárceles et al., 2022; Besó-Delgado et al., 2021), and there is no study exploring HPV self-sampling among immigrant populations. To address this gap, we carried out a mixed-methods study to explore the knowledge and perceptions of CC screening, and specifically, HPV self-sampling acceptability among Moroccan and Pakistani women residing in Spain.

Methods

Participants and research setting

We recruited first-generation Moroccan (N=36) and Pakistani (N=37) immigrant women aged 24-65 regardless of their CC screening status. We included women below the HPV self-sampling CC screening age (<30 years) to capture future willingness to participate in the programme. We combined purposive and snowball sampling as recruitment methods. Participants were recruited in socially deprived areas with high concentration of immigrants in the province of Barcelona. Recruitment was done predominantly through Moroccan and Pakistani key informant networks (e.g. religious and community-based associations) and in collaboration with community health workers in Barcelona. Further details about the methodology are available elsewhere (Lurgain et al., 2024).

Data collection

Focus groups and individual interviews

We conducted 8 focus group discussions (FGDs), each comprising 3-8 women and 22 semi-structured interviews (SSIs) between September and December 2022. Topics addressed knowledge on CC and screening, risk perceptions, women's attitudes towards HPV self-sampling and participants' preferences and ideas for implementing HPV self-sampling, as well as strategies to raise awareness about CC screening (see FGD and SSI topic guides in English in Appendices 3 and 6). All FGDs were held in convenient and familiar places for the participants (e.g., mosques or faith-based associations, community centres and health facilities) and were facilitated by two experienced community health professionals who shared language and cultural background with participants. The first author (JLG) and two research assistants (RAs) (KM and AS) conducted the SSIs at locations selected by participants (e.g., their homes, interviewers' home, religious and community centres). Towards the end of the FGDs and SSIs, women were shown two self-sampling devices: a swab (FLOQSwabs®, Copan, Italy) and a brush (Evalyn®Brush, Rovers Medical, The Netherlands), both validated for HPV detection on multiple PCR-based HPV assays (Hawkes et al., 2020). Subsequently, the discussion was focused on the HPV self-sampling and its advantages and disadvantages in the context of CC screening.

Self-sampling acceptability survey

All participants completed a short socio-demographic questionnaire, including previous attendance for CC screening and confidence of using HPV self-sampling (Appendix 8). All but two participants (one

pilot participant, one left the FGD early) were invited to use both self-sampling devices, which included written instructions in Spanish. Women were informed in advance that they were participating in a trial and would not receive their results but were offered the opportunity to schedule a clinician-based CC screening appointment. Those who accepted using one or both self-sampling devices were asked to complete a paper self-administered questionnaire for each self-sampling device, including nineteen questions assessing screening preferences, self-efficacy, trust in the test result, ease of use, feelings, duration, safety and receptiveness of each self-sampling device. The questionnaire was translated into Urdu and Arabic, as well as English and Spanish, and was assessed for comprehensiveness by bilingual research team members, external language ‘experts’ (a Moroccan medical student and a Pakistani Public Health doctoral student) and two participants. Women who declined to use either or both self-sampling devices were asked to record their reasons for refusing each device (see the acceptability questionnaires in English in Appendix 9).

Data analysis

Qualitative data analysis

All FGDs and SSIs were transcribed directly from Darija (Moroccan vernacular Arabic) and Urdu into Spanish and English, respectively. Thematic content analysis (Braun and Clarke, 2006) was conducted, combining inductive and deductive approaches, to identify themes and sub-themes. After initial familiarization and independent idea generation from first transcripts by the first author (JGL) and another investigator (PPT), potential themes and sub-themes were discussed and a codebook agreed. Transcripts were uploaded into the qualitative software ATLAS.ti (2023) for coding. Data from the women of both countries of origin were analysed in parallel.

Quantitative data analysis

Quantitative data from the questionnaires were collected and managed using REDCap web-based software platform (Harris et al., 2009; Harris et al., 2019). Socio-demographic and acceptability data were analysed through descriptive statistics restricted to the women who tried the devices using STATA 16 (StataCorp, 2019). Since the acceptability questionnaire was completed for each device individually, the quantitative results are presented separately for each device. The study was not powered to make statistical inferences and no statistical hypothesis testing was pre-planned, however in an ad-hoc analysis, Fishers Exact Test and Person's Chi-Squared Test were used to compare the acceptance rates between some characteristics such as country of origin, CC screening status, employment status, and time since migration to Spain. These results should be therefore interpreted with caution.

Data triangulation

A two-fold data triangulation process was performed: first, results from the FGDs and SSIs were compared to identify patterns of convergence and divergence; second, qualitative and quantitative data were compared for a comprehensive data analysis (Mays and Pope, 2000). To organise and present the findings, we used the theoretical framework of acceptability (TFA) proposed by Sekhon, Cartwright and Francis (2017).

Ethical considerations

The study was approved by the Research Ethics Committees of the London School of Hygiene and Tropical Medicine (26186), Bellvitge University Hospital (PR 140/22) and Vall d'Hebron University Hospital (PR(AG)317/2022). Each participant provided written informed consent prior to data collection and was given a 10-trip public transportation pass as compensation.

Results

Participants' characteristics

Socio-demographic details of all study participants (N=71; Moroccan: N=37, Pakistani: N=34), as well as of those who accepted to try at least one of the two self-sampling devices (56%, N=40), are summarized in Table 18. Participants' ages ranged from 24 to 65, with a median age of 40. Most (68%, N=48) were educated beyond secondary school, but only 18% were employed either formally or informally. Most were or had been married (94%) and had children (87%). Three quarters (around 75%) had lived in Spain for at least 5 years, but half needed a translator to a certain degree. Only 6% had never heard of CC screening and 72% had previously been screened.

Table 18 Socio-demographic characteristics of study participants invited for self-sampling and those who accepted the invitation by country of origin (N=71)¹.

	Total				Morocco				Pakistan			
	Invited for self-sampling		Accepted any self-sampling device		Invited for self-sampling		Accepted any self-sampling device		Invited for self-sampling		Accepted any self-sampling device	
	N	(%) ²	N	(%) ³	N	(%) ²	N	(%) ³	N	(%) ²	N	(%) ³
Participants	71	100%	40	56.3	34	100%	24	70.6%	37	100%	16	43.2%
Age median (IQR)	40	(34-48)	40	(35-46)	42	(35-48)	38	(34.5-47)	39	(33-46)	40.5	(37-44)
Age groups												
<30 years	8	11.3%	4	50.0%	3	8.8%	2	66.7%	5	13.5%	2	40.0%
30-39 years	26	36.6%	15	57.7%	12	35.3%	11	91.7%	14	37.8%	4	28.6%
40-49 years	21	29.6%	16	76.2%	10	29.4%	8	80.0%	11	29.7%	8	72.7%
>50 years	15	21.1%	5	33.3%	5	23.5%	3	37.5%	7	18.9%	2	28.6%
Level of studies												
No studies	8	11.3%	3	37.5%	6	17.6%	3	50.0%	2	5.4%	0	0.0%
Primary school	15	21.1%	11	73.3%	9	26.5%	8	88.9%	6	16.2%	3	50.0%
Secondary school	25	35.2%	12	48.0%	14	41.2%	10	71.4%	11	29.7%	2	18.2%
University or vocational training	23	32.4%	14	60.9%	5	14.7%	3	60.0%	18	48.6%	11	29.7%
Employment												
Employed (formal or informal)	13	18.3%	10	76.9%	11	32.4%	9	81.8%	2	5.4%	1	50.0%
Unemployed, housewives or retired	58	81.76%	30	51.7%	23	67.7%	15	65.2%	35	94.6%	15	42.9%
Marital status												
Single	4	5.6%	2	50.0%	4	11.8%	2	50.0%	0	0.0%	0	0.0%
Married	58	81.7%	32	55.2%	24	70.6%	18	75.0%	34	91.9%	14	41.2%
Separated, divorced or widowed	9	12.7%	6	66.7%	6	17.6%	4	66.7%	3	8.1%	2	66.7%
Children												
Yes	62	87.3%	34	54.8%	26	76.5%	19	73.1%	36	97.3%	15	41.7%

No	9	12.7%	6	66.7%	8	23.5%	5	62.5%	1	2.7%	1	100.0%
Time since migration to Spain												
≤5 years	18	25.4%	10	55.6%	10	29.4%	8	80.0%	8	21.6%	2	25.0%
6-10 years	19	26.8%	10	52.6%	4	11.8%	3	75.0%	15	40.5%	7	46.7%
>10 years	34	47.9%	20	58.8%	20	58.8%	13	65.0%	14	37.8%	7	50.0%
Translator necessity at health centre												
I always need a translator	18	25.4%	10	55.6%	7	20.6%	6	85.7%	11	29.7%	4	36.4%
Most of the times I need a translator	7	9.9%	6	85.7%	2	5.9%	2	100.0%	5	13.5%	4	80.0%
Sometimes I need a translator	10	14.1%	4	40.0%	5	14.7%	2	40.0%	5	13.5%	2	40.0%
I do not need translator at all	18	25.4%	12	66.7%	10	29.4%	8	80.0%	8	21.6%	4	50.0%
Self-perception of religiosity												
Very religious	22	31.0%	12	54.5%	12	35.3%	7	58.3%	10	27.0%	5	50.0%
Little or somehow religious	45	63.4%	24	53.3%	19	55.9%	14	73.7%	26	70.3%	10	38.5%
Cervical cancer screening status												
I don't know what CC screening is	4	5.6%	0	0.0%	0	0.0%	0	0.0%	4	10.8%	0	0.0%
Never screened	14	19.7%	10	71.4%	7	20.6%	6	85.7%	7	18.9%	4	57.1%
Ever screened ⁴	51	71.8%	29	56.9%	25	73.5%	17	68.0%	26	70.3%	12	46.2%
<i>Time since last screening test:</i>												
<1 year	14	27.5%	9	64.3%	8	32.0%	7	87.5%	6	23.1%	2	33.3%
1-3 years	20	39.2%	8	40.0%	11	44.0%	5	45.5%	9	34.6%	3	33.3%
3-5 years	9	17.6%	6	66.7%	2	8.0%	2	100.0%	7	26.9%	4	57.1%
>5 years	6	11.8%	4	66.7%	2	8.0%	1	50.0%	4	15.4%	3	75.0%

IQR: Interquartile range.

¹Due to missing data, the total percentages may not add up to 100%.

²Percentages calculated by column.

³Percentages calculated by row.

⁴Two participants did not recall time since last screening test.

Acceptability of HPV self-sampling

Concerning HPV self-sampling acceptability, results are described using both quantitative and qualitative data, and presented according to the seven constructs identified in the acceptability framework proposed by Sekhon, Cartwright and Francis (2017). Table 19 provides the definition of each construct and a summary of the qualitative findings with their corresponding selected quotes.

Table 19 Barriers and facilitators to HPV self-sampling acceptability.

Acceptability dimensions	Barriers & facilitators	Excerpts from FGDs & SSIs
Intervention coherence <i>(the extent to which the participant understands the intervention and how it works)</i>	<ul style="list-style-type: none"> Limited knowledge about cervical cancer and HPV 	<p><i>“My cousin told me a few days ago that this type of cancer exists, before I didn’t know about it” (SSI PC02, younger Pakistani woman).</i></p>
	<ul style="list-style-type: none"> Inadequate information about the screening test and confusion about the purpose of the test 	<p><i>“They only do this test when the woman is pregnant. If the woman is not pregnant, they don’t do this test (...) I did it and when I went to the doctor the next time, I asked for the test, and they told me that it’s not necessary” (SSI PC05, younger Pakistani woman).</i></p> <p><i>“I thought they were going to check my vagina and when they introduced the stick inside, I thought they were taking a sample to check about my baby, that’s it” (SSI PC02, younger Pakistani woman).</i></p>
	<ul style="list-style-type: none"> Misconceptions about risk to cervical cancer and HPV 	<p><i>“In my case, the probability to get this virus would be very low because, as I said, we are Muslim, and we only have this type of intimate contact with only one person in our entire life” (SSI PC04, older Pakistani woman).</i></p> <p><i>“The husband leaves God’s pathway and does something with another</i></p>

woman; then he comes back home 'dirty' and sleeps with his wife, and the poor woman doesn't know anything, and he passed his 'dirt' [virus] to her until it becomes cancer" (FGD 1, older Moroccan woman).

"In theory we all have to stay virgins before marriage, but I know about men who live here [in Spain] and they are not married and live with Latin women and then they go to my country [Pakistan] to get married" (SSI PC05, younger Pakistani woman).

Affective attitudes

(how an individual feels about taking part in an intervention)

- Preference for clinician-based over self-sampling

"I prefer to go to the gynaecologist because I will be 100% sure that the test is done correctly and the result is right" (SSI PC01, younger Pakistani woman).

"Personally, I would be afraid. I wouldn't dare to do it (self-sampling), I won't know how to do it, I prefer to go to the doctor" (FGD 3, younger Moroccan woman).

- Overcoming barriers related to shyness and offers privacy

"Some people feel shyness in front of doctors so that's the advantage of doing it at home" (FGD 3, younger Pakistani woman).

- Convenience, comfort, efficiency

"I prefer to do it at home, you are more comfortable, you can do it without feeling embarrassed and you can save time. It's something we can do it, it's not difficult" (FGD 3, older Moroccan woman).

- Overcoming barriers related to access

"It's much better to do it at home, you don't need an appointment with

health services (e.g. difficulties to get appointment)

the doctor... This kit is the solution for all the problems! I don't have to explain so many times at the reception of the CAP (primary health centre) the reasons for the appointment with the gynaecologist... This is perfect, even if I need to buy it, it's alright, I will pay, and everyone would pay" (SSI PC05, younger Pakistani woman).

Self-efficacy

(the participants' confidence that they can perform the behaviour(s) required to participate in the intervention)

- Lack of confidence to perform self-sampling correctly

"What if I don't get the sample correctly and I keep myself with the doubt? That's why I say that I'll be sure that the sample has been collected correctly with the doctor" (FGD 0, older Moroccan woman).

"It would take me hours only to think about it, whether to do it or not. I think it's difficult to do it by myself. I would ask my daughter whether I have done it correctly or not" (FGD1, older Pakistani woman)

- Fear of harming themselves

"People like me who don't trust themselves in things like this (self-testing) will feel insecure of not doing it correctly and harming themselves or feeling pain" (SSI PC06, younger Pakistani woman)

- Low literacy, specifically in relation to female anatomy

"European women, obviously, they will know how to use it (self-sampling test), but for Moroccans, most of Moroccans who live here (Spain) are from rural areas... I don't think they'll know how to use it. Many don't have studies; I don't think they'll know" (FGD 0, older Moroccan woman).

"I think due to lack of education, they won't perform it correctly,

which will affect the test results as well. It won't have any advantage of doing it at home" (FGD 0, younger Pakistani woman).

"I would go to the gynaecologist because I'm afraid of doing it by myself. I cannot read and I wouldn't understand anything" (SSI PC11, older Pakistani woman).

- Limited experience with tampons and vaginal products

"I'm very afraid of touching this intimate area, honestly. I've never been able to use a tampon. I have tampons and I would like to use them, but I couldn't. I am worried about this area, I need to care it very well, using quality pads, changing the panty. I cannot introduce anything in this area [vagina], you know? (...) I'm scared of introducing something and it'll stay inside, and I cannot take it out. Then, I had to go to the doctor... Honestly, I never was able to use a tampon" (SSI MC04, older Moroccan woman).

Perceived effectiveness

(the extent to which the intervention is perceived as likely to achieve its purpose)

- Distrust of the test result due to bad experiences with COVID self-tests

"These tests have advantages ... and disadvantages as well. My brother who is a doctor brought the kit to test for COVID and the result was positive and the second day when he bought it from the pharmacy it was negative. Either the device had a problem or maybe he cured the second day from COVID. You are not sure about these devices" (FGD 0, younger Pakistani woman).

"If it's a reliable test, I mean that it really detects the virus, then I may do it [self-screen]. But if it's like COVID tests, that sometimes detected the virus and other times

didn't, I wouldn't do it" (SSI MC11, younger Moroccan woman).

Opportunity costs

(the extent to which benefits, profits, or values must be given up to engage in an intervention)

- Reduced engagement with healthcare providers and missing the identification of other SRH issues

"If women can do this test by themselves at home, they will not go to the gynae anymore... and sometimes you go for one thing, and it turns out that you have other health issues" (SSI MC09, younger Moroccan woman).

Burden

(the perceived amount of effort that is required to participate in the intervention)

- Concerns about a positive HPV

"And the day I will get the result... God! I'll hope it's ok. Imagine if the result is not good [HPV positive], would you tell your husband?" (FGD 1, older Moroccan woman)

Ethical concerns

(the extent to which the intervention has good fit with an individual's value system)

- Belief that screening can affect virginity

"I'm still single, so I have never got screened. I cannot use this device as it can affect my virginity, you know?" (SSI MC11, younger Moroccan woman).

CC: Cervical cancer; FGD: Focus group discussion; HPV: Human papillomavirus; SSI: Semi-structured interview

Intervention coherence

Although most participants reported having undergone CC screening (72%) in the questionnaire, qualitative results revealed that knowledge about HPV, CC and CC screening was generally lacking among Moroccan and Pakistani women. Most of them were unaware that the screening test aimed to detect HPV infection, precancerous cervical lesions or even CC. FGDs and SSIs revealed that many participants believed that the test was part of routine pregnancy check-ups. Women explained that cytology was often opportunistically offered during pregnancy and two participants even believed that the test was to check on their babies. Overall, women reported receiving limited information and felt that doctors over-simplified their explanations about the test's purpose: *"They just told me that it's a women's health control to check that everything is ok" (SSI MC04, older Moroccan woman).*

Regarding CC, women often referred to CC as “*uterus cancer*” or as a cancer in the “*women’s intimate zone*”, “*women’s inner parts*” or simply “*down there*”. They perceived CC as a fatal or difficult to cure disease, associating it with pain, and believing that its treatment could cause infertility. Some women also linked CC to “*lack of hygiene*”, “*hormonal problems*” and considered it more common after menopause or in older ages.

Most participants were unfamiliar with HPV and unaware of its connection to CC. Those who knew about the virus had either been diagnosed with an HPV infection or encountered this term through their daughters’ school-based vaccination programmes. However, they reported not having information about HPV transmission, except a few women who linked CC to “*multiple sexual relationships*”.

After being informed that HPV is sexually transmitted, some women drew comparisons to other STIs, such as HIV. Moroccan and Pakistani participants showed a notably low perception of STI risks, believing that HPV is less prevalent in their communities compared to European populations. They attributed this to their cultural and religious values, such as virginity before marriage and having monogamous relationships, which they believed protected them from STIs. However, a few women from both communities questioned this belief, suggesting that certain husbands’ sexual behaviours could put their wives’ health at risk (see illustrative quotes in Table 19). None of the participants knew that HPV could remain asymptomatic and be transmitted after many years. They also believed that HPV was only transmitted through sexual intercourse with penetration, potentially diminishing their risk perception. A 34-year-old Moroccan participant, who self-identified as a lesbian, remarked: “*So, yes, after what you are telling me now [that HPV can also be transmitted through genital contact], I probably have it [the virus], yes*” (SSI MC08, younger Moroccan woman).

Overall, women from both cohorts had never heard about HPV self-sampling and they seemed not to share the same risk perception towards HPV infection as to CC. They perceived CC as a frightening disease that every woman is at risk of, but HPV infection was not considered a serious health treat. This misconception led them to express preference for cytology over a test to detect HPV: “*In my community, I think women would prefer to undergo the test to detect cancer instead of the one to detect the virus, because it (CC) scares them more*” (SSI MC11, younger Moroccan woman).

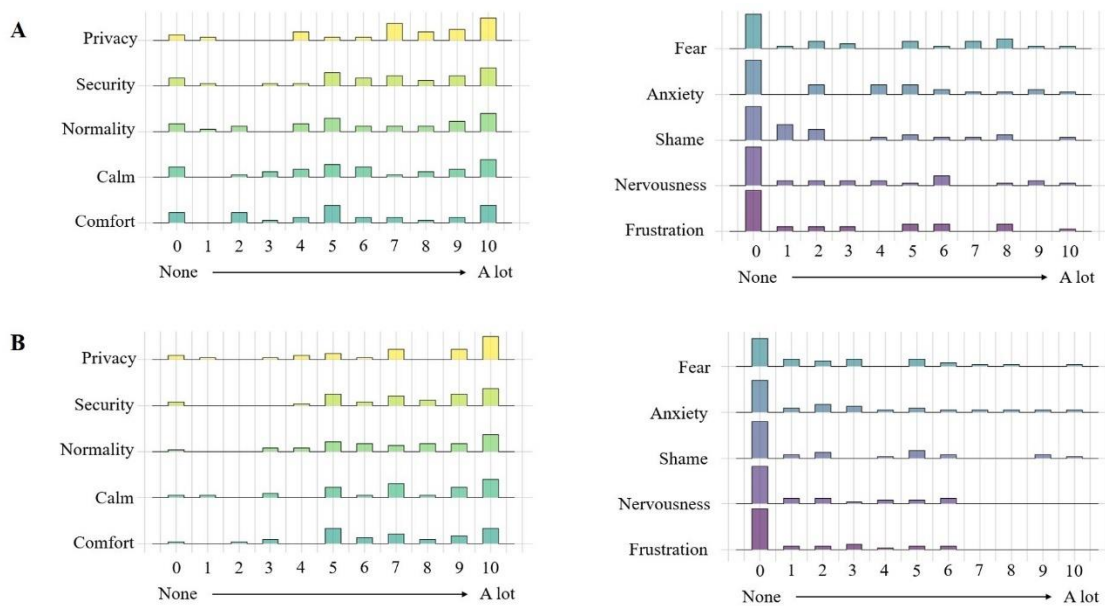
Affective attitudes

The first reaction of many participants from both Morocco and Pakistan was to express a preference for healthcare provider-based CC screening over self-sampling. Some women suggested that for a disease as serious as cancer, it would be safer to be screened by a doctor rather than themselves. By

the end of the FGDs and SSIs and after a short demonstration of the HPV self-sampling devices, 56% participants (N=40) accepted the invitation to take the devices home and tried at least one of the two self-sampling devices (Table 18). Among those, Moroccan women seemed to have a higher acceptance rate (71%), compared to Pakistani participants (43%) ($p=0.037$). Furthermore, HPV self-sampling acceptability was slightly higher among never-screened (71%) compared to those screened previously (57%) ($p=0.373$), although not statistically significant differences were found. Similarly, it was observed slightly higher acceptability among employed women (77%) compared to unemployed (52%) ($p=0.128$). No differences in acceptability were observed based on the time since migration to Spain (56%; 52%, and 59%, for less than 5 years, 6 to 10 years and more than 10 years in Spain, respectively) ($p=0.907$). Likewise, acceptability based on time since migration according to country of origin showed non-statistically significant differences ($p=0.086$). However, recently migrated Moroccan women (less than 5 years in Spain) showed higher acceptability (80%) than Pakistani women (25%) ($p=0.054$), indicating a trend towards statistical significance. Notably, all women who had never heard about CC screening refused to try the self-sampling devices.

During the FGD and SSI sessions, study participants mentioned several benefits about HPV self-sampling. They acknowledged the opportunity that HPV self-sampling brings to overcome barriers, such as shyness and being examined by a male doctor. In addition to the privacy that self-sampling offers, women also commented that performing the test at home is more comfortable and convenient, especially, for those women who have time constraints due to childcare responsibilities or full-time employment. Whereas older participants referred more often to overcoming shyness as the main motivator to use HPV self-sampling, younger participants from both cohorts emphasized that the main benefit of using self-sampling would be to remove accessibility barriers: they mentioned that self-sampling would be a solution for the long waiting lists that they often face in the Catalan health system to visit a specialist. The quantitative data on participants' feelings after undergoing self-sampling corroborate some of these findings: reduced levels of shame and increased feelings of privacy and comfort (Figure 6).

Figure 6 Density plots of women’s reported feelings experienced when collecting sample with swab (A) and brush (B).



The preference for clinician-based CC screening remained after trialling the self-sampling devices: more women still favoured clinician-based screening than self-sampling regardless of the device tried (39% and 34% for clinician-based and swab, respectively; 46% and 26% for clinician-based and brush, respectively) (Table 20). However, the participants who accepted the invitation to try the self-sampling devices generally showed a positive attitude towards HPV self-sampling, with a preference towards the swab. The majority would like to use the self-sampling device again, would recommend this sample collection method, and were receptive to use it as part of the CC screening programme (Table 20).

Table 20 Attitudes and usage experience among women who accepted self-sampling¹.

	FloqSwab®		Evalyn® Brush	
	N	(%)²	N	(%)²
Participants who accepted to use HPV self-sampling⁴	38	(53.5%)³	35	(49.3%)³
What would you prefer, self-sampling or having the sample collected by a healthcare provider?				
<i>Self-sampling</i>	13	(34.2%)	9	(25.7%)
<i>Healthcare provider-based</i>	15	(39.5%)	16	(45.7%)
<i>Both options are fine to me</i>	8	(21.1%)	7	(20.0%)
<i>None of them</i>	1	(2.6%)	1	(2.9%)
<i>I don't know / Prefer not to answer</i>	0	(0.0%)	1	(2.9%)
Do you think the self-sample has been collected properly?				
<i>Yes, I'm sure</i>	21	(55.3%)	13	(37.1%)
<i>I'm not sure I picked it up right</i>	16	(42.1%)	17	(48.5%)
<i>I'm sure I picked it up wrong</i>	0	(0.0%)	2	(5.7%)
<i>I don't know / Prefer not to answer</i>	0	(0.0%)	1	(2.9%)
Would you trust the result of this self-sampling test?				
<i>Yes</i>	19	(50.0%)	17	(48.6%)
<i>No</i>	11	(28.9%)	14	(40.0%)
<i>I don't know / Prefer not to answer</i>	5	(13.2%)	2	(5.8%)
Did you need any help to collect the self-sample or to understand the instructions?				
<i>Yes, to collect the sample & understand the instructions</i>	1	(2.6%)	1	(2.9%)
<i>Yes, but only to understand the instructions</i>	11	(28.9%)	13	(37.1%)
<i>No, I've done it all by myself</i>	25	(65.8%)	20	(57.1%)
What do you think about the use of the self-sampling?				
<i>I found it very easy, easy and simple to use</i>	27	(71%)	22	(62.8%)
<i>Normal, neither difficult nor very easy</i>	11	(28.9%)	7	(20%)
<i>I found it very difficult or difficult to use</i>	0	(0.0%)	5	(14.3%)
Do you think the self-sample device is safe?				
<i>Yes</i>	35	(92.1%)	25	(71.4%)
<i>No</i>	1	(2.6%)	6	(17.1%)
<i>I don't know / Prefer not to answer</i>	1	(2.6%)	4	(11.5%)
Would you use self-sampling again?				
<i>Yes</i>	36	(94.7%)	29	(82.8%)
<i>No</i>	0	(0.0%)	3	(8.6%)
<i>I don't know / Prefer not to answer</i>	1	(2.6%)	1	(2.8%)
Would you recommend self-sampling to a family or a friend?				
<i>Yes</i>	36	(94.7%)	29	(82.9%)
<i>No</i>	0	(0.0%)	3	(8.6%)
<i>I don't know / Prefer not to answer</i>	1	(2.6%)	1	(2.9%)
Would you like self-sampling to be used as a future screening method?				
<i>Yes</i>	35	(92.1%)	27	(77.1%)
<i>No</i>	1	(2.6%)	4	(11.4%)
<i>I don't know/ Prefer not to answer</i>	1	(2.6%)	2	(5.7%)

¹ Due to missing data, the total percentages may not add up to 100%.

² Percentages correspond to column percentage.

³ This percentage was calculated according to the total number of self-sampling acceptability study participants.

⁴ Number of participants who tried the devices was calculated based on the total study participants (N=71)

Self-efficacy

The main concern among participants regarding HPV self-sampling was the lack of confidence in their ability to correctly perform the sample collection. Quantitative data supported these concerns: prior to trying the self-sampling devices, almost half of the participants (45%) reported to be worried about not doing it correctly, whereas 42% felt confident as long as they had adequate instructions (Data not shown). Contrary to initial perceptions exposed in the FGDs and SSIs, more than half of the participants who tried the self-sampling devices felt confident (55%), but 42% of participants still reported feeling a lack of confidence in self-collecting the sample.

This lack of confidence led some women to express fear of harming themselves and to believe that a healthcare provider-based screening is safer and yields more reliable results. Quantitative data from the non-acceptability questionnaire is aligned with these statements and revealed that the main reasons for rejecting self-sampling devices among all participants were fear of collecting a vaginal sample by themselves (39% and 37% for swab and brush, respectively) and preference for clinician-collected sample (22% and 18% for swab and brush, respectively) (Data not shown).

Some participants attributed this lack of confidence to women's low literacy and language barriers. For example, a 49-year-old Moroccan woman expressed her concern about the difficulties that women from rural areas and with low literacy will face in understanding the self-sample instructions and performing the self-sampling. Quantitative data confirmed that around 60% of participants reported being able to understand the instructions and collect the sample without help (66% and 57% for swab and brush, respectively), but still around 30% of women reported needing help to understand the self-sampling instructions, which were only in Spanish (Table 20). Paradoxically, some participants with university studies and a good command of Spanish also reported not feeling confident about introducing any device into the vagina. For instance, a 40-year-old Moroccan woman argued that she never was able to use a tampon (see quotes in Table 19).

Overall, women who tried the self-sampling devices considered them safe and easy to use when evaluated quantitatively (Table 20). It seemed that women expressed a more positive response towards FLOQSwab® device compared to Evalyn®Brush device. However, given the limited number

of participants in our study and the focus on assessing overall acceptability, formal statistical comparisons between devices were not performed, limiting to draw firm statistical conclusions in this regard.

Perceived effectiveness

Half of the women who tried the devices expressed confidence in the results obtained from self-collected samples. However, around 30% had still doubts about the accuracy of the test results (29% and 40% for swab and brush, respectively) (Table 20). Distrust in the test result was not only motivated by the lack of confidence to self-collect the sample properly, but also by a broader lack of trust in self-sampling devices, influenced by negative experiences with COVID-19 self-tests (Table 19). These experiences heightened concerns about potential false negative results and the subsequent implications of delayed detection of an HPV infection.

Opportunity costs

Several women raised concerns that opting for self-sampling over clinician-based sampling might result in missed opportunities to check for other SRH issues, such as infections or other conditions. They emphasized the importance of being able to ask healthcare providers (nurses, midwives and/or gynaecologists) questions about, for instance, vaginal pain, contraception or pregnancy termination services, which women generally find difficult to book medical appointments for. A Moroccan participant specifically noted that gynaecology attendance might decrease if women can self-collect the sample for CC screening, potentially affecting overall health.

Another participant also highlighted the hygiene practices of health professionals, such as wearing gloves, and she suggested that undertaking the sample collection by themselves at home might not be as safe as in the health centre.

Burden

Regarding the potential burden that participants could feel if they undertook a self-sampling for HPV detection, a few women expressed their concern about the potential negative impact of a positive HPV test on their marital relationships, suggesting the psychological burden this could entail.

Despite the connection of CC with a STI and its potential stigma, Moroccan and Pakistani women perceived that HPV self-sampling would be positively accepted within their communities, including their husbands, if accurate and clear information about the risks and causes of CC, as well as the preventive purpose of the screening test were provided. However, a Moroccan participant pointed out

that some husbands would accept the self-sampling test only because it would prevent their wives from being examined by a male doctor.

Ethical concerns

Likewise, concerns about how CC screening (cytology or HPV self-sampling) could affect virginity were raised multiple times. For instance, a young Moroccan woman explicitly declined the invitation to use the self-sampling devices due to her belief that screening could tear the hymen and result in the loss of virginity (Table 19).

Enhancing HPV self-sampling implementation: women's insights

Raising awareness about CC and HPV

Women suggested that the most effective strategy for initial awareness raising for a CC screening program would involve listening to testimonies from women within their own community who had experienced either used HPV self-sampling or suffered HPV infection, cervical precancerous lesions or even cancer. Moroccan participants identified children's schools as ideal venues to reach immigrant women, as these women regularly take their children to school and could attend informative sessions or participate in informal talks with other mothers. Pakistani women proposed community and religious centres, especially mosques, as convenient locations for short health education sessions, as they are regular places for meeting and interact with other mothers. Additionally, educational activities organised by non-governmental organizations (e.g. Spanish/Catalan language classes) were highlighted as popular among immigrant women. Others pointed out the importance of engaging men in health education sessions to enhance the prevention of HPV and CC, recognising the role that men play in women's health decisions and practices.

CC screening invitation and delivery of HPV self-sampling devices

Most Pakistani participants expressed a preference for being informed about CC screening and HPV self-sampling by SMS. While Moroccan women also mentioned SMS, the majority preferred receiving information via letter or phone calls. They expressed concerns that SMS might not convey sufficient information and could be easily overlooked. Additionally, some participants in both groups considered that an in-person invitation from a health professional during a visit for some other health reason would be more effective than letters or SMS. Others emphasized that a group-based invitation during an informative talk or workshop would be the most effective approach:

“Personally I prefer a talk with other women, because each woman has her own experience and we can learn from each other”, (SSI MC04, older Moroccan woman)

“I think it should be through workshops as it’s easier to understand and you come to know about other women’s opinions as well”, (FGD 2, younger Pakistani woman)

Regarding the distribution of HPV self-sampling devices, pharmacies and health facilities were preferred options for both Moroccan and Pakistani participants. Pharmacies were seen as accessible and convenient locations, whereas healthcare facilities were perceived as more reliable due to their ability to ensure confidentiality. Both locations were valued for allowing women to receive instructions from healthcare providers and to clarify any doubts they might have.

Health professional and peer support during self-sampling

Respondents identified that overcoming the lack of confidence in correctly performing the self-sampling test could be achieved through the presence of a healthcare professional or a person with the same cultural and linguistic background, from their own community and adequately trained to explain the procedure. This support, even if provided at women’s home, was seen as reassuring. For instance, a few participants expressed a preference for performing the self-sampling with the assistance of their daughters, sisters, or someone in their own community, as it would make them feel more comfortable and confident.

Women also emphasized the importance of oral explanations and visual self-sampling instructions to overcome literacy and language barriers. Both groups proposed creating a didactic video in their local languages, offering detailed visual explanation of the self-sampling procedure. Moroccan participants proposed disseminating the video through community workshops and local TV channels. In contrast, many Pakistani women preferred accessing the video on their own mobile phones through WhatsApp or similar platforms. Younger participants also suggested the potential of social media platforms, such as Facebook, Instagram and Tik-Tok for distributing information and educational content.

Discussion

Our study is the first to examine HPV self-sampling acceptability among Moroccan and Pakistani women in Spain. We identified significant barriers to CC screening including lack of adequate information and misconceptions about HPV risk, which led some women to consider CC screening as irrelevant. Overall, participants expressed a preference for clinician-based sampling over self-sampling. Around half of the participants agreed to use HPV self-sampling and their experience was

generally positive. However, concerns about performing the test incorrectly and distrust in the test result were raised, which needs to be addressed prior to HPV self-sampling implementation among these two groups of women. Despite these concerns, women also described motivators for self-sampling and made some suggestions to enhance the newly organised population-based CC screening programme in Catalonia and screening participation within their communities.

In our study, HPV self-sampling acceptability seemed to vary based on country of origin, employment status, history of CC screening and time since migration to Spain. The overall acceptability rate in our population (56%) differs from previous studies on Spain-born women (Besó-Delgado et al., 2021; Ibáñez et al., 2023) and immigrants from those origins in other settings (Forrest et al., 2004; Hilverda, Fissers and Van den Broek, 2021), which reported over 80% willingness to undergo self-sampling. By country of origin, Pakistani women seemed to show lower HPV self-sampling acceptability (43%) compared to Moroccan women (70%), which is consistent with previous research conducted with Pakistani communities in the UK (Waller et al., 2006). This could be attributed to various factors. First, CC screening recommendations in the participants' countries of origin are different. Pakistan lacks official national screening recommendations (Chughtai et al., 2023), whereas Morocco started opportunistic screening of women aged between 30 and 49 (the age range of most women in our study) in 2010 (Arechkik et al., 2022), which may affect women's awareness about CC screening. This could also explain our findings of apparently higher acceptance of self-sampling among recently migrated Moroccan women compared to their Pakistani counterparts. Second, the long migration history of Moroccan women in Spain differs from that of Pakistani women, who arrived in the country relatively recently, which may affect immigrant women's acculturation and familiarity with the Catalan health system and, in turn, their acceptance of self-sampling.

Our quantitative findings also seemed to indicate that immigrant women with formal or informal employment had slightly higher acceptance of self-sampling compared to unemployed women, which may be explained due to higher social integration in the Catalan society and more access to health information sources, especially from the host country members. This finding also aligns with results from other studies in the Spanish context, where employment, educational level and nationality have shown to be some of the main determinants of CC screening inequities (Merino-Ventosa and Urbanos-Garrido, 2018). Similarly, it seems that the proportion of never-screened participants who took the opportunity to self-sample (71%) was slightly higher than those screened women (57%), despite being informed that they would not receive the test result. This supports the evidence that motivation to take part in screening may be higher in never- and over-due screened women when they are offered a choice (Drysdale et al., 2022) and when they feel that self-sampling helps them to overcome clinician-based screening barriers, such as shyness or discomfort (Arbyn et al., 2018).

The main barriers for HPV self-sampling were lack of adequate information about the purpose of the screening test, low risk perception and self-efficacy concerns. Women showed limited knowledge about CC and its connection with HPV, and the available screening services. Many women were unaware of the test purpose, and some confused it with routine pregnancy check-ups, potentially undermining their regular participation in CC screening programmes. Additionally, participants generally perceived their risk of HPV infection as low, as they reported not engaging in pre-marital sex or having multiple sexual partners, similar to findings in Canadian Muslim women (Vahabi and Lofters, 2016), leading some of them to believe that screening was irrelevant within their communities. This raises the need for more accurate, comprehensive, culturally and linguistically appropriate information to ensure '*intervention coherence*', so participants understand the importance of CC prevention, how HPV is transmitted and how CC screening programmes work, including HPV self-sampling.

Another important barrier that could affect participation in CC screening using HPV self-sampling was lack of confidence in self-collecting the sample correctly. In our study, around half of participants lacked confidence in their ability to self-collect the sample correctly – only 42% felt confident pre-trial, rising to over 50% among those who tried post-trial. This is consistent with a substantial body of literature that points to low '*self-efficacy*' as one of the major barriers for HPV self-sampling to be successfully implemented among minority ethnic groups (Hilverda, Fissers and van den Broek, 2021; Marshall, Vahabi and Lofters, 2019; Allen-Leigh et al., 2017; Cadman et al., 2015; Howard et al., 2009). This low perceived self-efficacy in performing self-sampling correctly led participants to express concerns about self-harm and distrust the test result. Overall, Moroccan and Pakistani women seemed to feel more confident using swab-based than brush-based vaginal devices, as seen in previous research (Szarewski et al., 2009).

Language barriers, low literacy and an apparent lack of experience using vaginal menstrual hygiene products, such as tampons, may explain this low self-efficacy perception among Moroccan and Pakistani women. The impact of lack of experience using vaginal products, such as tampons, was examined in a previous study conducted with Chinese participants in Canada, who were reluctant to perform the self-sampling procedure because of issues related to a lack of use of tampons in their community (Howard et al., 2009). In another study with Japanese women, researchers found that history of tampon use was only significant in relation to more negative perceptions of physician-led screening, but not for self-sampling. Additionally, lack of tampon use was not a barrier to willingness to use self-sampling again (Hanley et al., 2016). In line with these findings, our study participants who tried at least one self-sampling device showed a significant willingness to try it again. However, it is noteworthy that still around 30% of participants reported needing assistance to understand the instructions of the self-sampling devices provided only in Spanish, which is consistent with previous

research on immigrant populations in other settings (Devotta et al., 2023; Marshall, Vahabi and Lofters, 2019).

Beyond the lack of confidence in self-collection, other factors might impact women's '*perceived effectiveness*' regarding HPV self-sampling. In our study, several women questioned the validity of self-sampling devices due to their negative experiences with the accuracy of the COVID 19 self-tests, which led them to distrust and perceive HPV self-sampling as an ineffective method for early detection of CC.

Regarding the '*opportunity costs*' that women perceived in relation to the use of self-sampling as a primary sample collection strategy for CC screening, they mentioned the possibility of missing the chance of addressing other SRH issues during the screening visit (e.g. STIs, family planning). This concern was also identified in a recent intervention with immigrant women in Canada (Devotta et al., 2023). Other participants also noted that opting for self-sampling might decrease gynaecology attendance. Therefore, making it clear that self-sampling should not prevent women from consulting a healthcare provider or requesting a clinician-based screening, must be a priority to increase uptake and reduce health disparities.

We also identified an '*ethical*' concern regarding the use of HPV self-sampling. Participants, especially young women, explained that the use of vaginal devices may interfere with virginity making self-sampling unacceptable for them. On the other hand, we did not find that participants believed HPV self-sampling to incur a substantial '*burden*'. However, some women, particularly from the Moroccan cohort, raised concerns that a positive HPV test could negatively affect their marital relationships, potentially causing psychological distress. This concern was also identified in previous studies with immigrant women in the UK (Szarewski et al., 2009; Forrest et al., 2004), but also in autochthonous populations (Dodd et al., 2020; Bennett et al., 2019).

Despite the above concerns, Moroccan and Pakistani women highlighted various positive '*affective attitudes*' concerning the use of HPV self-sampling, such as the comfort, privacy, and convenience that this self-collection method offers, in line with previous research (Dieleman et al., 2022; Madzima, Vahabi and Lofters, 2017). Some women also mentioned that self-sampling could be a "solution" for the long waiting lists in the Catalan health system. In this sense, it is also crucial to acknowledge that self-sampling may also have the potential to overcome common health system accessibility barriers, such as lack of healthcare professionals.

Participants also expressed different preferences for educational interventions about CC prevention and HPV self-sampling implementation. For instance, Moroccan participants preferred school-based

interventions, whereas more Pakistani women favoured faith-based centres for awareness activities. Both groups of women agreed with the need of getting support from family and peers to overcome self-efficacy barriers to HPV self-sampling, an approach shown to be effective in recent interventions in India (Vahabi et al., 2023). Women in both groups also expressed a preference for culturally and linguistically appropriate audiovisual materials. This reinforces the importance of considering the communities' contexts when designing health prevention programmes, such as screening interventions, and the need of co-producing the intervention materials with the target population.

The main strengths of our study include the engagement of a diverse sample of Moroccan and Pakistani immigrants living in Catalonia, Spain, who were able to express their views in their own languages. This was facilitated by the availability of moderators and interviewers with the same cultural and linguistic backgrounds as the participants, which effectively created an environment of trust and comfort during the conversations. Cultural and linguistic alignment is crucial for ensuring honest and open communication, which enriched the data collected. Additionally, the combination of qualitative and quantitative methods provided a more comprehensive understanding of Moroccan and Pakistani women's perceptions and attitudes towards CC screening and, particularly, HPV self-sampling. While the qualitative methods (e.g. FGDs, SSIs) allowed us to explore anticipated reactions and intentions to use HPV self-sampling, the survey captured individual experiences and views on its use, as well as preferences regarding specific self-sampling devices. Our study's context, set within the implementation of a CC population-based screening programme in Catalonia, adds another layer of relevance and applicability to our findings. The timing of our research means that the insights gained can directly inform and improve the implementation of the CC screening programme, potentially increasing its effectiveness and uptake among these immigrant communities.

It is important to note that the number of women included in the qualitative component of our study was substantial, however the quantitative sample size was relatively small, limiting the ability to draw firm conclusions. Another limitation that needs to be mentioned is the use of convenience and purposive techniques for participant recruitment. These methods, while practical and often necessary in exploratory research, can introduce selection bias and limit the generalizability of the findings. In addition, we did not provide any test results back to the women, as self-samples were not processed for HPV detection, which may have discouraged some women from trying the devices. It remains unclear how this fact may have impacted participation and how many women would have accepted if the test was offered as part of the regular Catalan screening programme. All in all, this is the first study conducted in Spain addressing HPV self-sampling acceptability - including knowledge, perceptions, and attitudes - among Moroccan and Pakistani immigrant women and it provides invaluable insights into the health needs and expectations of Pakistani and Moroccan immigrant

women, serving as a starting point for future implementation research aiming to tackle CC screening inequities.

Conclusion

Efforts are still needed to raise awareness and empower Moroccan and Pakistani women living in Catalonia, Spain, with the provision of accurate and culturally appropriate information about the importance and benefits of CC screening. Women expressed their preference for clinician-based screening over self-collection, but there were mixed reactions towards HPV self-sampling. Around half of the study participants accepted the invitation to try self-sampling at home, but many raised concerns regarding self-efficacy which needs to be addressed to successfully implement an equitable population-based HPV self-sampling screening strategy. Tailored educational interventions, along with a community and/or peer-based approach appear to fit best to inform and educate women from Moroccan and Pakistani communities, foster confidence, and advocate for the uptake of HPV self-sampling.

Chapter 9 Discussion

In the era of cervical cancer (CC) elimination, this thesis contributes to the effort to eliminate health disparities regarding access to CC prevention services, by presenting the barriers, enablers, needs and lessons for the implementation of an equitable population-based screening programme in Catalonia, Spain. Using the cases of immigrant women from Morocco and Pakistan, I used a socioecological approach to explore individual, interpersonal and health system determinants of CC screening behaviours with the aim of informing future interventions to increase screening uptake in these two populations. This is the first study in Spain that examines HPV self-sampling acceptability among immigrant women. Despite HPV-based self-collection techniques having been demonstrated to be an acceptable and cost-effective strategy to increase screening uptake, this thesis critiques ‘one-size-fits-all’ approaches and provides important insights into barriers and facilitators to CC screening and, specifically, the benefits and challenges of the self-collection sample method from the perspective of Moroccan and Pakistani women, as well as healthcare providers. This thesis also contributes to the literature evaluating the potential effectiveness of SNA methods to better inform and design public health interventions (in this case, to prevent CC) and to increase intervention uptake.

This chapter is presented in seven different sections. First, a brief summary of the findings (9.1) will serve as a guide to the main points for discussion. Second, I will present the conceptual framework developed as a result of the study findings (9.2) and third, I will focus on the implications of the main findings (9.2). After this, I will provide a detailed list of long, medium and short-term recommendations for practitioners and policy makers (9.4) and highlight opportunities for future research (9.5). Finally, I will outline the strengths and limitations of the thesis (9.6) and conclude with a final message regarding the global goal of CC elimination (9.7).

9.1. Summary of findings

This qualitative-driven mixed-methods research study explored barriers and facilitators to CC screening among immigrant populations using the case of Moroccan and Pakistani women living in Catalonia, Spain. The study was conducted in various municipalities of Barcelona province and was nested within a broader implementation study of a newly introduced organised population-based CC screening programme, using HPV self-sampling as a primary self-collection method in this Spanish region. In this section, I will summarize the findings from Chapters 5 to 8 and organise them responding to the main research questions that structured this thesis. The first question asked about individual determinants of screening behaviours, such as health beliefs and attitudes towards self-care and prevention in general, and knowledge and perceptions of HPV, CC and screening, in particular.

The second question addressed the role of social norms and social networks on women's preventive health behaviours, specifically, CC screening. I illustrated here how the use of SNA methods provides a more comprehensive understanding of social interactions and potential influences on the health information and advice received by immigrant women, as well as their health behaviours. The third question was concerned with potential health system barriers to access and provide SRH services, especially CC screening. I presented the perspectives of immigrant women and healthcare professionals, focusing especially on the communication barriers that hinder access to quality care among immigrants and how to overcome them. Finally, the fourth question queried what potential effective strategies might increase Moroccan and Pakistani immigrant women's CC screening uptake, with special attention to the acceptability of HPV self-sampling as a primary sample collection method for screening.

1. What are the knowledge and perceptions of Moroccan and Pakistani immigrant women about CC and HPV, and screening programmes in Catalonia, Spain?

In Chapter 5 and 8, I provided critical insights into how cultural and religious values shape Moroccan and Pakistani women's understanding of health and risk perceptions, and how these affect their self-care and prevention attitudes and practices. Many women associated health merely with the absence of symptoms, which led them to seek care for treatment rather than to prevent a disease, and they prioritised care for their children and families over their own care. The assumption that cultural and religious practices, such as virginity before marriage and monogamous relationships, protect them against HPV infection led also women to have low risk perceptions and consider CC screening irrelevant within their Muslim communities. Lack of knowledge and awareness about CC and HPV, and inadequate information about the purpose of the screening test were also identified as barriers to CC screening among these two groups of women.

2. How do social networks influence on Moroccan and Pakistani immigrant women's preventive health behaviours and, specifically, their participation in CC screening programmes?

In Chapter 6, I provided the results of an egocentric network analysis of 22 respondents, alongside qualitative narratives and network graphs examining how migration shapes Moroccan and Pakistani women's social networks in Catalonia, Spain, and how these networks influence their receipt of health information and advice and shape their preventive health behaviours (i.e., CC screening). I showed that female immigrants from the participants' country of origin dominate Moroccan and Pakistani women's social networks in Spain and these immigrant peers, including in-laws and other relatives, are the most influential reference group for participants in terms of information and advice on SRH,

including CC screening and HPV self-sampling. The results also indicated that male partners play an important role in both facilitating and constraining women's access and use of healthcare services, such as CC screening.

3. What are the main challenges to the accessibility and provision of SRH services, especially CC screening, to immigrant women in Catalonia, Spain?

In Chapter 7, the findings suggest a communication breakdown between immigrant patients and healthcare professionals due to language limitations and cultural differences, which explains in part the knowledge gap mentioned in the above first research question. Here, I provided empirical evidence on how these intercultural communication barriers hinder the provision of and access to equitable and quality SRH services in the Catalan health system from both healthcare professionals' and Moroccan and Pakistani immigrant patients' perspectives. I described the implications of having limited or no capacity in the national language of their place of residence. This includes women's lack of autonomy to access healthcare services, and increased difficulties in interpersonal patient-provider relationship, leading women to perceive discriminatory attitudes from health staff, and making healthcare professionals have feelings of frustration and exhaustion as provision of care to immigrants often requires more time and effort. I also provided real-world experiences of cultural differences that contribute to hampering communication between immigrant patients and healthcare providers, such as religious and cultural taboos (e.g. difficulties to offer specific SRH services), gender segregation-related issues (e.g. preference for a female provider), and ethical concerns (e.g. informed consent, patient confidentiality).

4. Which strategies are most suitable to increasing Moroccan and Pakistani immigrant women's CC screening uptake? Specifically, what are the opportunities and challenges of HPV self-sampling as a primary sample collection method for CC screening?

Throughout Chapters 5, 6 and 7 I suggested various strategies based on the study findings and/or respondents' views that can contribute to increase CC screening uptake among these two immigrant communities. First, I proposed the establishment of an efficient call and recall system sending women culturally and linguistically appropriate invitations to arrange a CC screening appointment. Second, I noted that providers should be urged to recommend CC screening to their female patients. Third, I suggested the use of peer-based social influence approaches and 'word of mouth' communication strategies for information transmission and increasing awareness about CC prevention within these communities. Fourth, I proposed the deployment of sufficient intercultural mediator services in the Catalan health system and the establishment of cultural competence training for health staff. Finally, increasing the representation of minority ethnic groups in the health workforce was also suggested to

improve communication between immigrant patients and providers, and indirectly contributing to increase CC screening access and uptake.

In Chapter 8, I specifically focused on examining whether or not the implementation of HPV self-sampling was an appropriate strategy to increase CC screening participation among Moroccan and Pakistani immigrant women in Catalonia, Spain. The results show that self-collection poses its own opportunities and challenges. Women highlighted the privacy, comfort and convenience that these self-sampling devices offer. However, a significant number of women expressed their worry about their capacity to perform the self-sampling correctly, potentially harming themselves and the reliability of the test result. Other cultural and religious concerns, for instance, whether self-sampling could compromise virginity, were also raised.

I have argued that HPV self-sampling has the potential to increase CC screening uptake among these two specific immigrant populations as long as women receive accurate and, culturally and linguistically adequate information, and support from healthcare providers and/or trained peers to perform the self-sampling. Offering multiple options, such as home-based and clinic-based HPV self-sampling, or samples collected by healthcare professionals, could be an incentive for less confident women.

9.2 Conceptual framework

In this section, I present the conceptual framework adapted from the socioecological model (SEM) proposed by McLeroy et al. (1988) and developed as a result of the study findings. This ecological framework could help to guide future research to inform interventions to increase CC screening uptake among Moroccan and Pakistani women in Catalonia, as well as other immigrant populations in other Spanish regions. For instance, the conceptual framework proposes three key levels of analysis and specific constructs (e.g. risk perception, subjective norms, patient-doctor relationship) which can be applied to explore barriers and facilitators to CC screening in different immigrant populations.

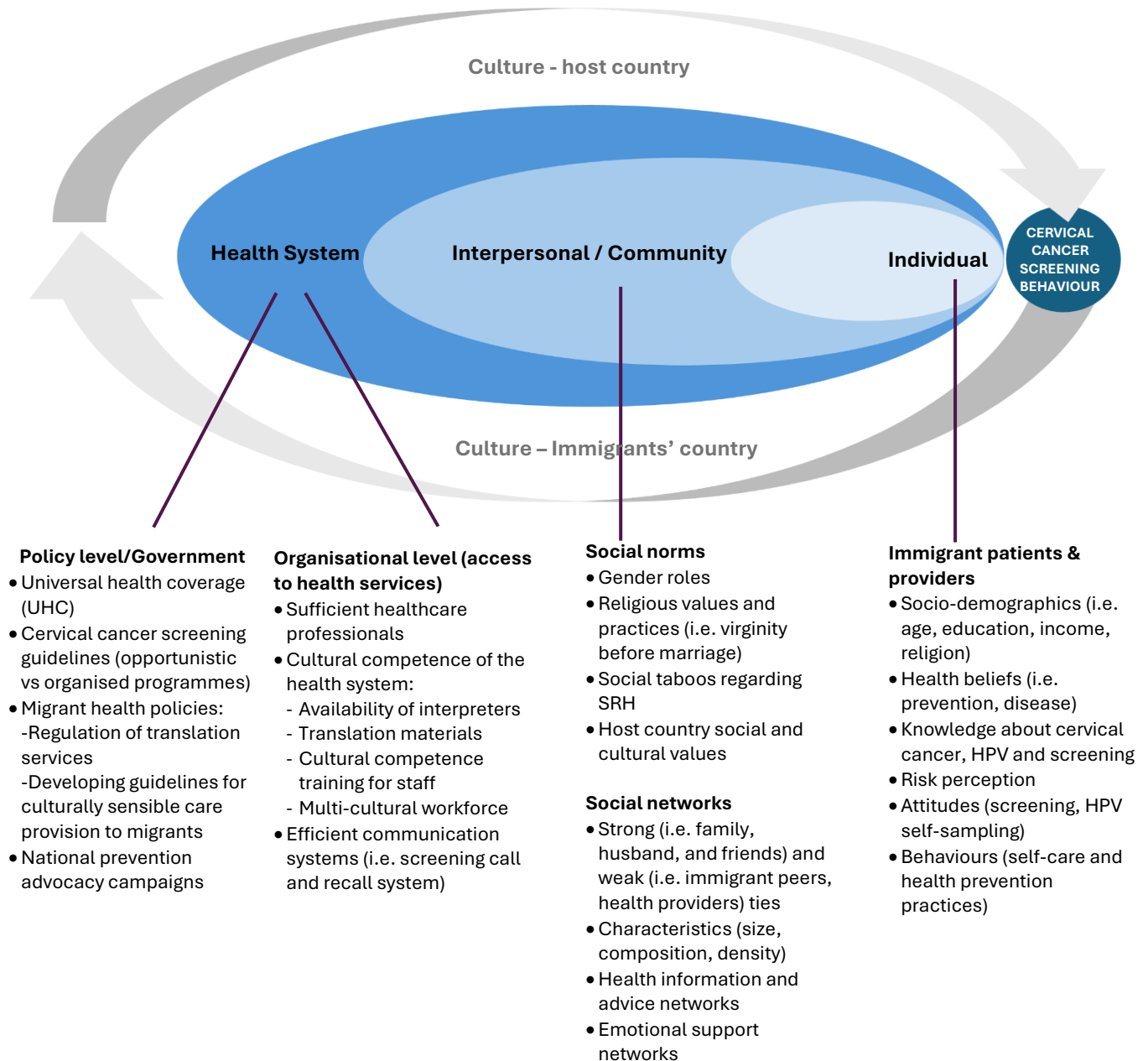
The conceptual framework (see Figure 7) draws on the ecological model and the theoretical approaches described in Chapter 3. The framework includes three main interrelated levels of analysis: individual, interpersonal/community and health system level. The interrelation of the factors influencing CC screening behaviours occurs within and between these levels. For instance, women's awareness of CC, HPV and screening can be explained by women's low individual literacy level, but it may also vary depending on the composition of their social networks (interpersonal/community level): those immigrant women with more Spanish contacts might have access to more diverse sources of health information compared to those women with family-centric networks. Similarly,

women's awareness of CC may also vary depending on the availability of intercultural mediator services or national campaigns to prevent CC in different languages (health system level).

The framework also includes the influence of overlapping cultures (*immigrants' culture* and *host country's culture*) on immigrants' CC screening behaviours at individual, interpersonal and health system levels. In the study, immigrants' culture influences their individual perceptions (e.g. risk perception towards HPV, perceived self-efficacy to use self-sampling), reflecting some of the Health Belief Model (HBM) constructs, as well as their social interactions, which reflects, in line with the theory of planned behaviour (TPB) and social norms theory, that both individual and social determinants affect women's CC screening behaviours. For instance, immigrant women construct the meaning of self-care and health prevention according to the social and cultural norms (e.g. gender roles, religious beliefs) created and transmitted within their social networks. The composition of these social networks (e.g. gender and ethnic homophilic relationships, dense family-oriented networks) are also shaped by women's culture and social norms, as well as the host country's culture (e.g. new relationships with other migrants, Spaniards). Likewise, their migration processes (e.g. family reunification) also influence women's social networks' composition. The framework applies social network theory principles by including the analysis of both social network structure (e.g. composition, size) and function (e.g. SRH information, emotional support) and its potential influence on women's CC screening behaviours.

Finally, the conceptual framework shows the importance of specific factors within the health system in relation to the migrant populations' needs (e.g. intercultural mediator services) and it applies a cultural competence approach guided by Betancourt et al.' (2003) framework. My study framework also reflects how the culture of the host country (e.g. linguistic and religious discrimination, racism) may affect CC screening behaviours at individual, interpersonal and health system level. Regarding the health system determinants, the framework proposes a multi-level analysis at organisational, clinical and structural levels, to identify potential interventions aiming at improving the cultural competence of the health system (e.g. communication between immigrant patients and healthcare providers, availability of translation services) in order to increase patient satisfaction and quality care, and also address health disparities in prevention services. The framework also focuses attention on the role of a range of policies concerning health prevention guidelines and migrants' health rights. It shows how these may also affect access to preventive health services and influence immigrants' screening behaviours. At this policy level, the advocacy role of governments in cancer prevention and other diseases is also relevant.

Figure 7 Conceptual framework for the determinants of cervical cancer screening behaviours among immigrant women -adapted from McLeroy et al.' (1988) socioecological model.



9.3 Implications of the findings

My thesis addresses persistent disparities in CC prevention programmes in the European region. Specifically, I questioned which research approaches and intervention strategies would be more likely to be most suitable and effective in increasing screening participation among vulnerable populations, such as immigrant women from low resource countries and low socioeconomic levels. Using the case of Moroccan and Pakistani women living in Catalonia, Spain, I identified cultural barriers to participating in CC screening programmes, such as different understanding of health and health priorities; sociocultural values shaping self-care and health prevention attitudes and practices; potential influences of social norms and social networks on CC screening behaviours and misconceptions about the risk of HPV infection in Muslim communities, leading some women to deem CC screening irrelevant.

I will first discuss the importance of culture in the design of public health interventions and the urgency of improving cultural competence throughout the health system to ensure an equal provision of quality care to optimise CC screening coverage among high-risk populations, such as socioeconomically challenged immigrant groups. Second, I will examine intervention approaches to increase immigrant women's CC screening uptake, followed by the Moroccan and Pakistani women's preferences and views for a CC prevention intervention in the context of Catalonia, Spain. Third, I will discuss the combination of educational and behavioural or social influence interventions to improve Moroccan and Pakistani immigrant women's participation in CC screening, and the use of SNA methods to better identify, reach and engage communities. Fourth, I will discuss opportunities and challenges for future participatory interventions with these two specific Muslim communities, based on the learnings obtained during my data collection in Catalonia, Spain. And finally, I will reflect on to what extent HPV self-sampling is suitable for Moroccan and Pakistani immigrant women and to what extent essential implementation principles, such as adaptability, can be incorporated into the newly introduced Catalan organised population-based CC screening programme, which use HPV self-sampling as a primary self-collection method.

9.3.1 Culture matters

The findings of this thesis agree with much past work on the important role of culture in health behaviours and practices, use of and access to healthcare, health decision-making and, ultimately, health outcomes (Napier et al. 2014; Edberg, 2013; Betancourt and Flynn, 2009; Helman, 2007). As explained in the Introduction, for the purpose of this thesis, culture is not only considered a set of values and beliefs socially transmitted within a group of people who share the same racial heritage or ethnic identity, but as an ecological and dynamic system shaped by the environment, political history,

religion, language, and social structures (Hammond, 1978; Bronfenbrenner, 1994, Kawaga-Singer et al., 2010, 2012).

Using the case of Moroccan and Pakistani immigrant women in Catalonia, Spain, I identified multiple barriers and facilitators to CC screening influenced by women's cultures. I discuss these and how certain cultural aspects could be susceptible of change to help increase CC screening uptake. In this sense, it is important to note that although Moroccan and Pakistani women are predominantly Muslim, they differ in many ways, culturally and in their migration history to Spain. For instance, whilst the Moroccan community is the largest and oldest group of foreign immigrants in Spain (excluding Latin Americans), the Pakistani community is still a relatively new and small group, a difference that might influence women's screening behaviours, as well as their knowledge and perceptions about CC screening.

Self-care and prevention attitudes and practices

Previous research has reported the perception that certain immigrant populations are not prevention-oriented and that this attitude contributes to their low participation in screening for cancers (Marques et al., 2023). My argument here is that these cultures are prevention oriented, but in different ways. For instance, self-care and prevention went beyond a simple focus on healthy lifestyle (e.g. physical leisure activities) for Chinese immigrants in Australia. They also emphasized the need to maintain emotional and social harmony and balance in their lives, and doing medical check-ups was mainly for illness management rather than prevention (Kowk et al., 2007). This means that self-care and prevention concepts often used in Western countries, such as healthy lifestyle and regular health check-ups, may not be meaningful for some specific cultural groups.

In my study, Moroccan and Pakistani women's understanding of health as merely the absence of symptoms led them to seek care only for treatment rather than prevention. For instance, they reported that in their countries people do not have the habit of undergoing check-ups, which apart from cultural factors, could be explained by other determinants, such as their experience with the health system in their own countries, where screening programmes are limited or private. Furthermore, women described a more collectivist concept of self-care and prevention: they de-emphasized and sacrificed their own (health) needs for those of their family, in opposition to more individualistic Western self-care and prevention practices. This attitude, found also in other cancer-related studies with immigrant women in the US (Carrol et al., 2007, Ashing et al., 2003), may be influenced by the gender norms embedded in societies with traditional and patriarchal structures, such as in Morocco and Pakistan, where women play an important caregiver role.

Religious beliefs and practices also shaped Moroccan and Pakistani women's preventive health behaviours. On the one hand, beliefs that cancer or other health problems are "God's will" or a punishment from God for religious failures have been reported as a barrier to preventive care in previous studies with different Muslim communities (Ahaddour and Broeckaert, 2018; Padela et al., 2018, 2012; Morrison et al., 2013; Abdullahi et al., 2009). On the contrary, other studies have emphasized that there are several aspects of the Muslim faith that can be used to support screening, such as requirements of honouring God through cleanliness and maintaining good health, avoiding risky health behaviours or taking medication as needed (Ahaddour and Broeckaert, 2018; Redwood-Cambell et al., 2011).

In my study, I identified both perspectives in the Moroccan and Pakistani participants' narratives. Many of them believed that health and illness are "God's will", but women also supported the idea that individuals should use the means that God provides for prevention, treatment and cure, referring to screening services, doctors, or medication. Regarding religious practices, women mentioned the prohibition of alcohol and extramarital sexual relationships, and the value of virginity before marriage as common protective or health prevention practices in their communities. While these practices are demonstrated to be beneficial and health-protecting, they significantly reduced women's risk perception toward HPV infection, as occurred in other Muslim populations and with other STIs, increasing their risk of remaining underdiagnosed (Alomair et al 2023, 2020; Pratt et al., 2019). Although it did not emerge from the study findings, it is important to remind other religious practices, such as male circumcision, which act also as protective factor against HPV (Shapiro et al., 2023).

Overall, Moroccan and Pakistani women did not perceive HPV as prevalent in Muslim communities as in European societies, which led some participants to see CC screening as irrelevant. On the other hand, the value of virginity in these cultures also may deter sexually active young women (e.g. second-generation immigrants) from screening as it might stigmatise them within their communities. These cultural and religious aspects should be taken into consideration when designing CC screening interventions, but also when working with Muslim immigrant communities as there may be opportunities for cultural change and, consequently, improve CC screening participation.

Sex segregation

Sex segregation, a common cultural practice in both Morocco and Pakistan, emerged as an important factor that not only shaped the composition of women's social networks - dominated by female contacts - and the health information and advice they received, but also influenced women's

preference for same-sex healthcare professional, which is given a greater importance in religio-cultural environments where seclusion and separation of genders are societal norms.

First, my social network analysis supports the evidence that associates gender and ethnic homophily with immigrant populations (Zhao, 2023; Vacca, Cañarte and Vitale, 2022; Van Tubergen, 2015; Rostila, 2010). However, it does not agree with the negative influence that this homophilic pattern may have on migrants' access to and use of care, as reported by previous studies in Sweden and China (Lin et al., 2020; Åkerman et al., 2016).

When members of a cultural group migrate, their cultural values and beliefs may change over time due to the adoption of practices or technologies from other cultural groups in the host country. Failure to acknowledge the effects of accommodation to other cultures and the fluidity of cultural beliefs and practices may lead to erroneous presuppositions and stereotyping patients and their families from particular cultural groups (Kawaga-Singer et al., 2010, 2012), but also it may lead to undermine the potential benefits of these overlapping cultural systems in migrants' access to and use of healthcare.

In the case of Moroccan and Pakistani immigrant women, I identified an opportunity to leverage newly formed, but still ethnically homophilic, peer connections to replace older normative views about preventive health behaviours with new ones, which might result in better access to healthcare and, ultimately, increased CC screening uptake. For instance, I showed how women relied on their female immigrant peers, especially those with more experience in Spain and better understanding of the Catalan health system, to get information and advice on SRH matters, including CC screening and HPV self-sampling.

Second, it is well established in the CC screening literature that women prefer being examined by a female healthcare professional to avoid embarrassment regardless their cultural background (Srinath et al., 2023). My findings confirmed this, but also revealed that cultural and religious norms regarding sex segregation affect women's access to healthcare and specifically, SRH services. Although most Moroccan and Pakistani participants reported not having any problem being examined by a male provider if there were no choice, they acknowledged that there were cases of women in their communities that needed the husband's approval to attend a gynaecology appointment.

This is consistent with previous research, in which husbands pose a barrier to engaging with care, particularly found in research from Africa, South Asia and South/Central America, where men have more power and receive more priority than women (Devotta et al., 2023; Lau et al., 2022; Vega Crespo et al., 2022). However, my social network analysis also identified a husband's potential role as health promoter. Some women, particularly in the Pakistani group, explained how their male partners

encouraged them to self-care and to go for general check-ups, but this excluded women's SRH issues, a health area in which Moroccan and Pakistani men appeared poorly engaged due to cultural taboos, except when the couple faced fertility problems, or the woman was pregnant.

It is worth mentioning the different levels of autonomy to make SRH decisions between Moroccan and Pakistani immigrants. I observed that most Pakistani participants reported making all their health decisions together with their husbands, whereas Moroccan participants considered women's health issues to be personal and many of them emphasized that the decision over whether or not to get screened for CC was theirs to make. These differences could be explained by the length of stay in the host country and the accommodation to a Western culture (Spain) where women have more autonomy. While Moroccan women have a long history of migration to Spain, Pakistani women are still a small group in this country.

Intercultural communication barriers

Finally, my findings showed important communication barriers between immigrant patients and healthcare providers due to language and cultural differences, hindering access to and provision of quality healthcare, which is consistent with previous migrant health literature (Lebano et al., 2020). In my thesis, I used the case of the primary care SRH centres (ASSIR units) in the Catalan health system and I presented the perspectives of immigrant patients and healthcare providers together to facilitate a more comprehensive analysis. For instance, I identified feelings of discrimination from both sides. On the one hand, immigrant women reported discriminatory attitudes, especially at a clinic's reception, when booking gynaecology appointments and/or expressed their preference for or requested a female provider. On the other hand, healthcare professionals interpreted a patient's refusal of care on the basis of gender as gender discrimination. This contentious issue regarding the sex of the provider is well documented by Aubrey et al. (2017) in a narrative review.

Feelings of frustration were also identified from both sides. On the one hand, women reported disappointment and a certain lack of trust in the health system, as they felt that providers did not give them sufficient time to explain their health problems and oversimplified their explanations about, for example, the purpose of the CC screening test. On the other hand, healthcare professionals reported feeling frustrated and exhausted as immigrant patients with limited language skills required longer consultation times and greater effort to communicate with them, and even when basic understanding was achieved, communication barriers persisted due to cultural differences. For instance, providers lacked confidence in offering certain SRH services (e.g. termination of pregnancy) that immigrant patients could consider offensive or against their religion. The limited availability of intercultural mediators and translation services also led immigrant patients and healthcare providers to use

informal interpretation services, such as family members, friends, or healthcare staff (e.g. nurses), which compromised patient confidentiality and informed consent.

In sum, the thesis demonstrates how individual beliefs and sociocultural values and norms may influence CC screening behaviours at individual (e.g. self-care and health prevention practices), interpersonal/community (e.g. health decision-making processes) and health system (e.g. patient-provider relationship) levels. My main argument is that increasing Moroccan and Pakistani women's CC screening uptake in Catalonia goes beyond opportunistic culturally sensitive interventions and requires also political commitment to improving the cultural competence of the whole health system. This has various implications for practitioners, policy makers and researchers.

First, it is necessary to understand culture beyond a specific ethnic or racial identity, and to acknowledge the overlapping cultures of the immigrant populations (shaped by their own cultural background, the immigration stage, socioeconomic characteristics, literacy rate, etc.). This will require better dialogue with these populations and facilitate opportunities for patient engagement in health services research acknowledging the differences between immigrant groups, in this case from Morocco and Pakistan.

Second, it is crucial to accompany health policies for immigrants with real actions on the ground, such as the regularization of intercultural mediator services, the inclusion of regular cultural competence training sessions for health students and staff (including providers, managerial, public health and administrative personnel), and developing clear guidelines to address cultural conflicts (e.g. sex of the provider issues). In addition to these specific cultural competence interventions within the health system, responding to diversity will require increasing migrants' health literacy and their participation in the development and implementation of health policy (Mladovsky et al., 2012). As Ingleby (2012) stated, "if migrants are not consulted and involved in the design of their own health services, the services will not be optimally accessible and inclusive, which will lower the performance of the health system". Therefore, "the integration of migrants into health systems can only take place through dialogue, in which both sides show respect for each other's views". This implies a shift from a 'cultural competence' to a 'cultural humility' approach. For instance, Lekas, Pahl and Lewis (2020) propose training providers in 'cultural humility', that is, an orientation to care that is based on self-reflexivity, appreciation of patients' lay expertise, openness to sharing power with patients, and to continue learning from one's patients. Finally, a commitment to improving access and provision of healthcare services to immigrants also implies addressing old health system deficiencies, such as insufficient time per patient, saturation, inadequacy of resources or poor professionals' working conditions.

Ignoring the above implications in the provision of SRH care, in particular CC screening services, and in the design of preventive health interventions, will contribute to perpetuating CC screening disparities among immigrant populations and, also make the health system less cost-effective over time.

9.3.2 What interventions work to increase cervical screening uptake?

A number of systematic reviews have examined the effectiveness of multiple health promotion interventions to increase CC screening uptake among immigrant women in the last two decades (Alam et al., 2023; Greenley et al., 2023; Mann et al., 2015, Lu et al., 2012). The majority of the identified interventions involved education and information provision, in combination with other aspects, such as reminders, support for navigating the screening pathways, financial incentives and behavioural or social influence techniques, such as motivation, persuasion, role modelling via survivors, celebrities and narrative videos. Various meta-analyses of these studies have suggested that community-based, culturally sensitive and multi-component interventions are the most effective approaches (Alam et al., 2023; Brevik, Laake and Bjørkly, 2020; Mann et al., 2015). However, intervention effectiveness may vary with ethnic population and study setting (Lu et al. 2012). Thus, qualitative research prior to intervention is a crucial initial step for a successful implementation, to which this thesis contributes.

Community-based participatory interventions have been one of the most common approaches to increase screening uptake among immigrant populations, especially in the US -these interventions are very limited in Europe (Greenley et al., 2023). Based on the available literature, these interventions engaged with and trained trusted women from the immigrant communities - usually referred as “lay health advisors/workers”, “*promotoras*”, “patient navigators”, “community champions” or “community health workers” (CHW) - to better reach the target population and maximise the impact of the intervention (Devotta et al., 2023; Lewis-Thames et al., 2022; Wong et al., 2021, Chan and So, 2020; Qureshi et al., 2019; Han et al., 2017; Luque et al., 2017; Mock et al., 2007). For instance, in an intervention conducted in Canada with a diverse group of immigrant women from West/South Asia, Middle East and North Africa, the use of “community champions” was shown to be effective in engaging women to talk about CC and encourage them to get screened, as women felt more comfortable and safe speaking with them (Devotta et al., 2023).

In my study, consistent with the literature, Moroccan and Pakistani women expressed their preference for community-based and in-group activities with other women, such as informal talks or more organised workshops, to receive information about CC and HPV-based screening. They emphasized the importance of learning from other women “like them” (referring to the same cultural and linguistic

background) and who have experienced CC themselves or in their close social circles and/or who were more knowledgeable about the Catalan health services.

Culture is often regarded as a barrier to health behaviour, but, as I demonstrated in the previous section, it can also be used in interventions as a positive health resource (Bond and Brough, 2007). Evidence suggests that incorporating the culture of the target population in health interventions can be more effective than a 'one-size-fits-all' approach in reducing health disparities (Torres-Ruiz et al., 2018). Culturally tailored interventions involve the adaptation of the study design, materials, messages and other components of the intervention to reflect the cultural needs and preferences of the target population (Joo and Liu, 2021; Pasick, D'onofrio, Otero-Sabogal, 1996).

Many of the culturally tailored interventions to increase CC screening uptake identified in the literature consisted of adapting CC preventive messages and education materials to the language, culture, and religion of the target populations. They used audiovisual (i.e. video-clips, films), oral (i.e. face to face or online sessions) and written (i.e. brochures) communication channels, and were co-designed with immigrant women (Hamdiui et al., 2022b, 2022c; Christie-de Jong et al., 2022, Power et al., 2020; Ochoa et al., 2019; Pratt et al., 2017, 2020; Luque et al., 2017). Various co-designed interventions with immigrant Muslim women incorporated faith-based messages (Hamdiui et al., 2022b; Christie-de Jong et al., 2022) and engaged faith leaders (Pratt et al., 2017).

In my study, Moroccan and Pakistani women expressed their preference for verbal and visual communication materials to learn about the importance of CC screening and how to use a HPV self-sampling device. In almost all FGDs, participants raised concerns about the language barrier and they emphasized the urgent need to develop materials translated into their local languages. In line with the above interventions, women from Morocco and Pakistan also suggested that their religion could be a positive 'tool' to encourage women in their communities to self-care and get screened for CC. Regarding intervention delivery, I identified differences between Moroccan and Pakistani women: whereas Pakistani participants considered the mosque an appropriate setting to reach women and implement a health prevention intervention, Moroccan participants mentioned their children's school or community centres, rather than faith centres.

Finally, evidence indicates that combined interventions, including health education and behavioural or social influence components, are more effective than single interventions. For instance, a few interventions focused the motivational component on healthcare providers (Møen et al., 2020) and other behavioural interventions engaged Latina immigrants' partners in the education sessions (Jandorf et al., 2012). In my study, Moroccan and Pakistani women considered healthcare

professionals, especially primary care providers, and their immigrant peers and husbands, to be the contacts most influential on their health behaviours, as I will explain in detail in the following section.

9.3.3 Leveraging social networks

My thesis illustrated the potential use of SNA research methods to better identify influential contacts, and better inform the design of behavioural interventions to prevent CC, as well as to design strategies to reach and engage communities in intervention implementation.

Research on the influence of SNA on health behaviours has grown in the last two decades (Smit et al., 2020; Shelton et al., 2019; Hunter et al., 2019). For instance, several studies have demonstrated that close friendships were more likely to influence adolescents' smoking behaviour than peers outside their network (Pollar et al., 2010; Alexander et al., 2001), and other health prevention studies have shown greater improvement of risk behaviours among adult network members when the intervention was built off of an existing social network (e.g. peer educators intervene with their network members) (Booth et al., 2011; Latkin et al., 2009). Research has also suggested that social network characteristics, such as peer selection and homophily may influence the spread of obesity among adolescents and adults (Christakis and Fowler, 2007; de la Haye et al., 2010, 2011).

In the case of CC prevention research, studies examining the effect of subjective social norms in women's CC screening behaviours have shown that the intention of women to adhere to screening guidelines was greater when family and friends were perceived to approve of screening (Griva, Anagnostopoulos and Madoglou, 2010; Allen, Stoddard and Sorensen, 2008) and when their social contacts (e.g. sisters) were screened (Keating et al., 2011). Other studies examined the structure of the women's social networks and found that women with a higher proportion of weak ties (e.g. neighbours) in their immediate networks were more likely to get screened for CC than those with a higher proportion of close ties (e.g. family) (Luque et al., 2016).

In terms of intervention implementation, the interest in the strategic use of SNA approaches to increase intervention uptake (e.g. HIV self-test, HPV self-collection sample) has also grown (Hu et al., 2024). Some studies have suggested the potential for interventions that harness social networks to change health behaviours, especially among peer and friendship networks (Jeon and Goodson, 2015). For instance, Wanyenze et al. (2022) used a peer-based approach to promote and increase uptake of CC screening within the community. In this study, conducted in Uganda, women from the community who had been screened for CC were trained to engage in CC prevention advocacy within their social networks. They were asked to recruit up to three social network members ('alters') who had not yet been screened for CC. After 6 months of the program, intervention 'alter' participants were more

likely to have been screened for CC compared to control ‘alters’ [67% vs. 16%]. The intervention also revealed significant increased engagement in CC prevention advocacy among the trained women and the ‘alter’ participants, suggesting the importance of word-of-mouth communication in specific communities (Wagner et al., 2023).

The findings of my egocentric social network analysis can help inform the design of future CC screening interventions with Moroccan and Pakistani women in Catalonia, Spain. First, as explained previously, participants expressed a significant degree of trust in their female immigrant peers in Spain to share SRH information and advice, which is in line with other studies with immigrants in the US (Menjivar, 2002). Second, consistent with recent literature (Ozturk et al., 2024), women also relied on healthcare providers, but in this case, participants especially mentioned those who belonged to their immediate family circles. And third, I identified two conflicting influencing roles of the husband: as a health promoter and as a barrier to health service use.

Based on this evidence, the strategic utilisation of immigrants’ social networks has strong potential to be effective for future behaviour change interventions to increase CC screening uptake among these two communities in Catalonia, Spain. First, participants’ female immigrant peers may play a positive role in disseminating accurate information, and raising awareness about the importance of CC screening and fostering a shift in perceptions and health prevention behaviours. Specifically, engaging immigrant peers with longer exposure and more experience with the Catalan health system in the transmission of CC prevention information could be an effective approach. Second, the engagement of male partners in CC awareness campaigns and educational interventions may also contribute to an increase in women’s screening uptake. As my study showed, husbands can play a relevant health promoter role in encouraging women to self-care and do regular health check-ups (e.g. CC screening). Although this is a controversial approach in Western countries, as some healthcare practitioners advocate for prioritising only the empowerment of women, a growing body of studies with immigrant populations supports this intervention approach. For instance, research conducted in Norway evaluating the effect of a community-based intervention to increase CC screening uptake among immigrant women concluded that “it might have been positive to include the male members of the Somali and Pakistani communities and give them information on CC screening and why it is necessary” (Qusheri et al., 2021).

In sum, my findings are aligned with previous evidence and indicate that peer-based multi-component educational interventions in combination with behavioural or social influence techniques seem the most appropriate approach to raising awareness and increasing CC screening uptake among these two specific communities.

9.3.4 Participatory approaches: opportunities and challenges

The use of peer-based health prevention interventions is not a straightforward strategy. These interventions require the adoption of participatory approaches, which can be challenging, taking into account that immigrant populations are often considered ‘hard-to-reach’ populations and difficult to recruit into research studies (Samsudeen, Douglas and Bhopal, 2011; Saghaghi, Bhopal and Sheikh, 2011).

Participatory approaches involve collaboration with the individuals whose lived experiences and actions are the subject of study, as active partners who share power and influence over research processes, including the formulation of the research question and aim, the development of a research design, the selection of appropriate methods for data collection and analysis, the implementation of the research, the interpretation of results and dissemination of findings (ICPHR, 2013, Bergold and Thomes, 2012).

Participatory approaches include a range of methodologies from community-based participatory research (CBPR) (Minkler and Wallerstein 2008; Horowitz, Robinson and Seifer, 2009) and action research (Koshy, Koshy and Waterman, 2011) to patient & public involvement (PPI) to co-production practices (Health Research Authority 2021; Frasmann, 2018). As mentioned previously, community engagement and participatory approaches have been shown to improve the effectiveness of health interventions, as well as provide benefits to participants themselves, such as improving health behaviours and self-efficacy (O’Mara-Eves et al., 2013, 2015), while also contributing to the addressing of health disparities (Roura et al., 2020;).

Currently, a significant emphasis is being placed on ensuring PPI in health interventions and research, especially with vulnerable groups, such as immigrant populations from low resource settings and low socioeconomic levels (Rustage et al., 2021). However, despite the potential benefits of these participatory methods, its application in real-world interventions pose challenges, especially with immigrant populations. Migrant health researchers have emphasized the need to design context-specific participatory interventions, evaluating the best approach in each setting and with each specific population (e.g. degree of participation of individuals, who should be involve, in which phases) (Rustage et al., 2021; Roura et al., 2020).

Based on my fieldwork observations and experiences during data collection, I have found potential opportunities and challenges in conducting community-based participatory interventions with these two specific groups of women. My findings show that the majority of Moroccan and Pakistani women interviewed individually expressed willingness to become ‘champions’ of CC prevention, sharing

information with other women in their communities about the importance of screening and encouraging them to get screened. These positive attitudes to engage and contribute to the development of future interventions concerning their health suggest that participatory-based interventions with these two populations is feasible. Nonetheless, I also identified several potential challenges when applying participatory techniques with these two immigrant groups, such as ensuring a fair representativeness of the populations, burden on participants and maintain necessary engagement prior, during and post-intervention, as well as operational difficulties (e.g. language barriers).

With regard to the first challenge: the recruitment of participants for a future community-based intervention with Pakistani and Moroccan women in Catalonia should be carefully considered to ensure a fair representativeness of the population. To understand immigrants' socialization patterns and associations' landscape, their role, functions and linkages with the broader communities is crucial to decide the type and level of participation that suits each specific intervention setting and to avoid tensions among participants. Key questions, such as *What type of community organizations exist?* *What type of activities do they conduct?* and *Who participates in them and why?* could help to ensure that all views of the immigrant community is represented (Rifkin et al., 1986).

In the case of Moroccan and Pakistani immigrant women in Catalonia, both groups are very heterogeneous in sociodemographic terms, but also in their socialization patterns. For instance, even though the affiliation to faith-based associations or religious centres (mosques) seemed to be common among Pakistani women, this did not necessarily mean that all of them shared the same interpretation of the religious norms (e.g. use of the hijab), which could generate tensions during the intervention. This community fragmentation might thus make it more challenging to ensure a fair representation of the population. On the other hand, Moroccan women seemed to have varying socialization patterns: very few study participants reported attending mosque regularly, but they acknowledged that women in their communities, especially the more recently arrived immigrants, did. Women were not necessarily affiliated with Moroccan community associations in Catalonia, but they seemed to take part in activities organised by these associations and also by the Catalan community centres in their neighbourhoods. These varying patterns of socialization might also pose issues regarding the representation of the population.

Second, the burden on participants is another potential issue to conduct participatory interventions with Moroccan and Pakistani women in this specific setting. The assumption that participants will have the necessary time available for contributions is another challenge highlighted in the literature (Horowitz et al., 2009). In the case of Moroccan and Pakistani women, willingness and positive

attitudes to contribute to the development of a CC screening intervention may not be translated into practice in real-world as easily as researchers and/or public health practitioners might expect.

As explained in previous Chapters, women in these two communities play an important caregiver role and time for themselves was reported to be limited. This was reflected during the data collection phase. For instance, the FGDs and SSIs had to be conducted during children's school hours and in convenient places within their neighbourhoods. Time availability and flexible timetables are, therefore, an imperative to implement participatory interventions with these two communities of women and maintain necessary engagement prior, during and post-intervention. Moreover, it will be important to take into account religious events, such as Ramadan, and the mobility of migrants - women often travel to their home countries for long periods (1-2 months), especially during the Spanish summer -, as these may imply disruptions of the intervention activities. Thus, adaptation is also crucial for genuine participatory-based interventions.

Finally, the challenge of working with communities in which the dominant language of the researchers and/or public health practitioners, and immigrant communities differ has also extensively been documented in the migrant health literature (Rustage et al., 2021; Roura et al., 2020). To identify bilingual research assistants with oral and written skills was challenging in my study context, where two official languages co-exist (Spanish and Catalan). The incorporation of second-generation immigrants to future CC screening interventions targeting first-generation immigrants is also imperative to help with communication. However, this might generate tensions if both groups do not share the same views regarding, for example, the risk of HPV infection or the need to get screened.

9.3.5 Is HPV self-sampling an acceptable strategy for all?

Effective implementation of organised population-based CC screening programmes requires societal acceptance and local ownership. To achieve this, it is necessary to reduce barriers to participation, collaborating with local civil society organisations, and increasing population confidence (Lynge et al., 2012). In the case of immigrant communities, as this thesis shows, each ethnic group faces unique barriers to acceptance of and participation in CC screening programmes using HPV self-sampling.

As previously mentioned, Pakistani women still comprise a small community group in Spain and most of the women in the study had arrived recently in the country. This lower exposure to the host country's culture might explain, for instance, why Pakistani participants seemed to show lower acceptability rate than Moroccan participants to use HPV self-sampling for CC screening (43% vs 71%). Similarly, despite having higher education levels, Pakistani participants also seemed to have lower confidence in performing the self-sampling properly (perceived self-efficacy) than Moroccan

participants (out of 21 women who reported to be confident using the swab-based self-sampling, 14 were from Morocco (67%) and 7 from Pakistan (33%)), suggesting less familiarity with the use of vaginal products, as previous studies have reported (Arshad et al., 2020).

Acknowledging these migration and cultural differences, in this thesis I have aimed to identify common features that could be used to inform the design of future culturally sensitive interventions to increase CC screening uptake using HPV self-sampling among immigrants from different Muslim backgrounds. Overall, I identified three main common challenges and facilitators: first, women in both communities reported having inadequate information about CC screening and showed low risk perception towards HPV infection due to the belief that certain religious practices are protective; second, low self-efficacy to perform HPV self-sampling correctly was the main concern in the two groups of women, which could explain participants' preference for clinician-based screening; and third, participatory peer-based multi-level interventions focused on improving women's health seemed to be the most suitable approach to increase CC screening participation and encourage the use of HPV self-sampling among both immigrant groups.

Women also expressed their views and suggestions about the new population-based CC screening programme, which will recommend HPV self-sampling as a primary sample collection method for CC screening to all women between the ages of 30 and 65. As explained in the Introduction, the programme plans to invite women to CC screening through SMS, after which they will collect self-sampling devices and return the samples to a nearby pharmacy. Results will be provided through a digital health app if the result is negative and by phone if it is positive. The possibility to request clinician-based screening will also be available.

In light of my findings, the Catalan population-based screening programme would need to use multiple ways and languages for invitation to CC screening to reach some immigrant populations. While Pakistani participants expressed a preference for SMS to receive information and be invited to CC screening, Moroccan women raised concerns that SMS might not convey sufficient information and could be easily overlooked. They preferred a letter or a phone call to be invited for screening. Regarding the distribution of HPV self-sampling devices, most women agreed with the option proposed by the new Catalan screening programme and they considered pharmacies an accessible and convenient option. Regarding the test result, again some women might find difficulties to access the digital app and it would be more convenient to communicate the test result by phone or letter in their local language.

Finally, some studies (Marlow, Drysdale and Waller, 2024) found that offering a choice (i.e., self-sampling or clinician-based screening), as the Catalan screening programme contemplates, could

cause worry for some women and many would prefer a recommendation. Supporting women to make a choice could be, therefore, an important aspect to take into account, especially for women with lower levels of education. Although by the time of the data collection it was not clear whether the Catalan screening programme would offer a choice and, therefore, women did not express their views in this regard, many participants were open to use HPV self-sampling as long as they receive the necessary support.

The main implication of these results for the implementation of an equitable and effective organised population-based CC screening programme in Catalonia, is the need to adapt these homogenous programmes to the specific immigrant women's needs, which would require the provision of more flexible services, including multiple ways of invitation for screening, as well as screening choices with appropriate support to ensure informed decisions.

The incorporation of the following two principles: adaptability and flexibility, to the newly introduced Catalan organised CC screening programme, would contribute not only to reducing barriers and increasing acceptability and confidence in the use of HPV self-sampling among these immigrant populations, but ultimately to eliminate health disparities in CC prevention.. However, since economic limitations and political decisions dictate what is feasible, this shift from a uniform to a more personalised and flexible screening approach in the context of the Catalan health system might be compromised.

My final argument is, therefore, that the flexibility and adaptability of organised population-based CC screening programmes to immigrants' needs should be a priority in order to eliminate persistent disparities in CC prevention, but also to reduce health system costs in the long run. This would help to meet the CC elimination goal, nationally and globally. However, political commitment and adequate financial resources are needed to not only implement cultural sensitive interventions to increase immigrants' CC screening uptake and the use of HPV self-sampling, but also to improve the cultural competence of the health system, by starting, for instance, with basic and urgent measures such as the translation of the HPV self-sampling instructions into languages other than Catalan and Spanish.

9.4 Recommendations for policy makers and practitioners

A detailed list of recommendations based on the findings presented and discussed in the previous sections is provided for the use of policy makers and practitioners to improve immigrants' participation in CC screening programmes in Catalonia, Spain, and beyond. General strategies and specific actions are proposed in Table 21.

Table 21 Recommendations to improve immigrant women's access and use of cervical cancer screening services.

General strategies	Specific actions
Health system	
<p>1. Financing and policies to develop a migrant-friendly healthcare system and ensure access to preventive services (Long term)</p>	<ul style="list-style-type: none"> • Standardise the provision of intercultural mediators across the health system (e.g. establish a budget, provide training in intercultural mediation). • Ensure culturally and linguistically appropriate information materials (e.g. HPV self-sampling instructions). • Standardise the provision of cultural competence training for health staff, including physicians, nurses, administrative and receptionist staff. • Develop clear guidelines for healthcare providers to help manage cultural challenges and/or conflicts (e.g. the sex of the healthcare professional).
<p>2. A surveillance system to monitor migrants' cervical cancer incidence, mortality and screening coverage (Short/Medium term)</p>	<ul style="list-style-type: none"> • Improve the primary care SRH centres' (ASSIR units) data systems and collect information on cervical cancer incidence, mortality and screening coverage among immigrant women.
<p>3. National information and awareness campaigns to prevent cervical cancer (Short term)</p>	<ul style="list-style-type: none"> • Consider the integration of cervical cancer screening information campaigns into schools' HPV vaccination campaigns.
<p>4. Availability of clear information about the different cervical cancer screening choices available and provision of recommendation (Short term)</p>	<ul style="list-style-type: none"> • Provide women with clear information about the available screening methods (e.g. Pap smears, home-based HPV self-sampling, clinician-based HPV self-sampling) and how to request the chosen option and give recommendation or support to ensure informed decisions. • Offer HPV self-sampling devices in multiple places (e.g. children's schools, community and faith centres). • Adapt and send invitations for CC screening in multiple ways (SMS, letter, phone calls) and multiple languages.

Interpersonal/Community	
5. Community participation in health promotion programmes (Short/Medium term)	<ul style="list-style-type: none"> • Involve community ‘champions’ (e.g. female immigrant peers) to provide information about cervical cancer prevention and screening choices within the communities and influence the change of normative beliefs about self-care and prevention practices, such as screening behaviours. • Evaluate and support the engagement of husbands and male partners and family members in cervical cancer prevention programmes.
Individual	
6. Women’s health empowerment (Short term)	<ul style="list-style-type: none"> • Provide in person and in group sessions accurate and culturally appropriate information about the cervical cancer screening procedure and, in particular, HPV self-sampling. • Provide individual support (e.g. health providers, trained peers) to those women who face more challenges in using HPV self-sampling.

9.5. Opportunities for future research

I have identified several significant gaps throughout this study that should be further explored in future research:

1. With regard to the relevant role played by husbands in certain patriarchal societies concerning women’s health decisions, men’s knowledge and attitudes about CC prevention and screening, especially in Western countries, remains unexplored. The findings of this study identified the potential role of male partners in enhancing women’s CC screening uptake. A few studies have been conducted in LMICs to explore husbands’ knowledge and attitudes regarding CC screening (Dsouza et al., 2022a; De Fouw et al., 2023; Okedo-Alex et al., 2020; Binka et al., 2019). However, further research is needed in Western countries to better understand immigrant men’s social norms around spousal support for preventive health behaviours and to capture their perspectives on CC screening. Such insights will allow us to assess the appropriateness and feasibility of incorporating male partners into CC screening interventions in Catalonia, Spain, and beyond, and especially among older generations of immigrant women, as their partners might have more influence.

2. This study showed the importance that first-generation immigrants from Morocco and Pakistan give to the transmission of their traditional and cultural values to their children. For instance, women's narratives emphasized the value of virginity before marriage in these societies and their concerns about the belief that CC screening, especially using HPV self-sampling devices, may affect their daughters' virginity. Although it is often assumed that second- and third-generation immigrants would adopt the host country's values and behaviours, which would reflect higher participation in CC screening programmes than among their mothers and grandmothers, in fact the above traditional values and beliefs (e.g. virginity) might deter sexually active young Muslim immigrant women from CC screening, to avoid tensions with their families or stigma within their communities. Therefore, future CC prevention research must include not only first-generation, but also later generations of immigrant women in order to explore their beliefs, attitudes and behaviours regarding HPV-based screening and vaccination. This would help to better understand their CC screening behaviours and the extent to which their families and communities' social norms influence them.
3. This thesis illustrated the potential of SNA methods to identify sources of health information and advice among immigrant women, as well as the influence of social network members on women's self-care and preventive health behaviours. For instance, my egocentric social network analysis revealed how participants mainly trusted in their immigrant peers for SRH information and advice. Therefore, CC screening programmes, especially those interventions targeting immigrant groups, who are often tightly connected communities, could benefit from SNA research methods. This social network approach would allow for a better understanding of the social interactions of immigrants and identify key contacts, leaders or 'champions' within the communities that may influence women's CC screening behaviours.
4. Finally, continued research addressing the specific disparities in screening participation among immigrant populations is needed. Specifically, further qualitative and mixed methods studies are needed to examine the acceptability and feasibility of HPV self-sampling among immigrant women. Equally, community-based interventions to increase CC screening uptake should evaluate the effect of such interventions in different immigrant groups and especially in the European context. Cost-effectiveness evaluations are also needed to inform CC prevention policies.

9.6. Strengths and limitations

I will summarise here the most relevant strengths and limitations of the study as a whole.

A significant strength of the study was the mixture of multiple research methods and sources of information. The combination of qualitative, quantitative and SNA methods provided a more comprehensive understanding of the factors influencing Moroccan and Pakistani women's CC screening behaviours. For instance, the social network data shed light on the characteristics of immigrant women's social networks and potential social influences on women's self-care and prevention attitudes and practices, and the triangulation of qualitative and quantitative data allowed to contrast women's attitudes and intentions to use HPV self-sampling and their actual decision and experience with two specific devices. The use of FGDs and SSIs also benefited the recruitment of immigrant women, who were able to choose how to participate in the study. In addition, whereas FGDs allowed to capture women's social dynamics, SSIs provided more personal accounts. Furthermore, the inclusion of immigrant women's and healthcare providers' views also enriched the data and allowed for a deeper understanding of the individual, interpersonal and health system determinants pertaining to the accessing and using of CC screening services. For instance, as shown above, I was able to compare immigrant patients' and providers' perceptions and experiences within the Catalan health system, and their recommendations for future interventions to increase immigrants' participation in CC screening programmes reflected both women's own preferences and the professional perspective of healthcare providers.

Other strengths were the sample's diversity and the availability of moderators and interviewers with the same linguistic and cultural background as participants. Regarding the sample: although second-generation immigrants were excluded from this study, I was able to recruit immigrant women with a wide range of ages, educational levels, length of residency in Spain, living in the capital city and semi-urban areas. This diversity allowed for the capturing of different views and experiences, as well as the meaningful comparison of women's social networks. The inclusion of community health providers and two RAs from the same immigrant communities was also crucial to build rapport with the participants and foster an environment in which they felt comfortable to openly share their views in their own languages, as well as in Spanish for those who were proficient. This sense of community helped to encourage women to try the HPV self-sampling devices.

This exploratory research, the first study in Spain evaluating the acceptability of HPV self-sampling among immigrant populations, was carried out in collaboration with the Catalan Institute of Oncology (ICO), which is currently leading the implementation of the organised population-based CC screening programme in the Catalonia region. This research collaboration will enhance the impact of my study

and facilitate the translation of my findings into practice. For instance, as a result of my study, the CC screening programme in Catalonia, led by ICO, will develop culturally adapted informational materials and implement community-based interventions to increase CC screening uptake among Moroccan and Pakistani groups in various municipalities of Barcelona. These interventions will then be evaluated in order to integrate any necessary adaptation or change into standard practice across a wider population.

A few limitations should be considered when interpreting the findings. First, since my study only targeted Moroccan and Pakistani immigrant women, the results require careful attention, considering potential similarities and differences, in order to be transferable to other relevant immigrant groups with low CC screening participation rates in Catalonia - for instance, Chinese and Senegalese women. Nonetheless, my findings provide in-depth insights into the barriers and facilitators to CC screening of these two specific communities and identify common features (e.g. communication barriers) which should be taken into consideration when designing CC screening interventions for immigrant populations. Furthermore, investigating two different groups of immigrants added depth to my research and helped in the elucidation of some similarities and differences, and increase applicable knowledge. Moreover, the findings may be transferable to similar contexts across Catalonia, as well as other regions in Spain, and allow scaling up interventions targeting these two populations.

Second, despite the diversity of the sample (e.g. age, levels of education), married women with children and screened for CC were highly represented, and second- and third-generations of immigrants were excluded. Furthermore, the participants' screening status was not taken into consideration for recruitment purposes. Therefore, women in this study may not be representative of all Moroccan and Pakistani immigrant women living in Catalonia, Spain, especially of those who are under-screened. Similarly, the fact that all the healthcare professionals interviewed worked in areas with high concentrations of immigrants, could have omitted the opinions of those providers' who work in areas where immigrants are less well represented. In terms of the sample size, qualitative interviews reached data saturation. However, quantitatively the sample was too small to allow for formal statistical analysis on the acceptability of HPV self-sampling and the SNA sample (N=22) also restricted the measurement of the effect of informational and normative influences on participants' CC screening behaviour, a consideration which was beyond the scope of this thesis. Additionally, the use of overlapping samples -for instance, the same women who participated in the FGDs and SSIs responded the acceptability survey questionnaire- could have biased the results and limit their extrapolation to other women who were not exposed to information or discussed attitudes towards HPV self-sampling prior to the survey. Nevertheless, the descriptive statistical analyses established a foundation for future survey studies.

Social desirability bias may be another limitation: the presence of research team members might have influenced women to provide a more closely opinion to a 'Western' viewpoint than otherwise would have done, particularly, in regard to the influence of religion on health behaviours. To mitigate this potential bias, however, I carefully designed the research tools addressing high sensible questions (e.g. religion related) at the end of the discussions and experienced healthcare professionals from the participants' communities were responsible to moderate the group sessions.

Finally, although two coders were involved in the development of the codebooks, only one researcher completed the coding. Greater engagement of other researchers might have enhanced the analysis and avoided potential subjective bias. Due to logistical and funding constraints, and to avoid respondent burden, respondent validations (e.g. sharing results with participants) were not sought. However, all the findings presented in the manuscripts were contrasted with and reviewed by the research team in Barcelona.

9.7. Conclusions

The findings of this thesis show multiple determinants of health and health behaviours through the case of Moroccan and Pakistani immigrant women's participation in CC screening programmes in Catalonia, Spain, and support a more sociological approach (Short and Mollborn, 2015) to address behaviour change, examining individual actions in context. This includes individual characteristics (e.g. age, education, knowledge, perceptions), along with social (e.g. family, friends, community norms, social influences) and health system (e.g. institutional organisation, policies) factors.

The results also emphasize the importance of culture in shaping behaviours at each of the above ecological levels, for instance, in women's self-care and prevention attitudes and practices, the composition of women's social networks, and women's interaction with the health system. This has significant implications for reducing health inequities in preventive care and, specifically in the design and implementation of equitable CC screening programmes in Spain and beyond.

The findings also suggest the need for community-based participatory approaches from a human-centred design perspective for culturally sensitive interventions seeking to increase CC screening uptake among immigrant women. Multi-component interventions combining educational activities and behavioural techniques seem the most suitable for immigrant groups. Furthermore, political commitment towards a more culturally competent health system is an imperative to improving access to quality SRH preventive care, especially CC screening.

In the specific case of HPV self-sampling as a primary self-collection method for CC screening, this thesis concludes that the adaptation to the needs of high-risk population groups, such as immigrant women, must be a priority for all European governments, including the Catalan government, to eliminate CC screening disparities and provide equitable preventive services. This implies the need for greater effort in raising awareness about the importance of screening in these communities, fostering confidence in the use of HPV self-sampling devices, and flexibility in the provision of CC preventive services, for instance, by offering multiple CC screening choices (e.g. home-based and clinic-based self-sampling, clinician-based screening) through multiple channels (e.g. community ‘champions’, healthcare providers). This would ultimately help to achieve the global goal of eliminating cervical cancer in the following years.

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Appendices

Appendix 1 Budget for data collection.

	Units	Frequency (hours)	Rate (EU) per hour	Rate (GBP)	Total GBP
FGD (3 with Moroccan women and 3 with Pakistani women)					
Personnel					
Moroccan CHAs and/or ICMs (FGD moderation/note-taking)	2	4	€ 10,00	£ 8,30	£ 66,40
Pakistani CHAs and/or ICMs (FGD moderation/note-taking)	2	6	€ 10,00	£ 8,30	£ 99,60
Arab-Spanish or English transcriptions/translations	1	32	€ 10,00	£ 8,30	£ 265,60
Urdu-Spanish or English transcriptions/translations	1	48	€ 10,00	£ 8,30	£ 398,40
Training					
1-day training (7 hours per day)	4	7	€ 10,00	£ 8,30	£ 232,40
Venue and participants compensation					
Venue & refreshments for FGD	6		€ 30,00	£ 24,90	£ 149,40
Transport compensation	80	1	€ 10,00	£ 8,30	£ 664,00
Sub-total					£ 1.875,80
SSI (social network data collection 8 with Moroccan women and 8 with Pakistani women)					
Personnel					
Moroccan CHA or ICM (interview participants)	1	10	€ 10,00	£ 8,30	£ 83,00
Pakistani CHA or ICM (interview participants)	1	10	€ 10,00	£ 8,30	£ 83,00
Arab-Spanish or English transcriptions/translations	1	120	€ 10,00	£ 8,30	£ 996,00
Urdu-Spanish or English transcriptions/translations	1	120	€ 10,00	£ 8,30	£ 996,00
Training					
1-day training (7 hours per day)	2	7	€ 10,00	£ 8,30	£ 116,20
Participants compensation					
Transport compensation	16	1	€ 10,00	£ 8,30	£ 132,80
Sub-total					£ 2.407,00
TOTAL FIELDWORK DIRECT COSTS					£ 4.282,80

Appendix 2 Outline of the research training and pilot sessions of the research instruments.

Training and pilot sessions prior to data collection (September, 2022)

Date/Time	Activity
6 Sept, 15.30 – 20.00	Training session – DAY 1 Agenda: 15.30 Welcome & introductions 15.35 Brief presentation on cervical cancer and screening 15.50 Q&A 16.00 Study objective(s) and research tools 16.15 Basic ethical aspects 16.30 Semi-structured interview: practical tips 17.15 BREAK (snacks and beverages will be provided) 17.25 Network Canvas and social network mapping 18.10 SNA protocol: practical tips 18.30 Practical activity ('play role') 19.30 Coordination of pilot interviews and recruitment of participants 20.00 Close
7, 8, 9 Sept	RAs' practice: pilot interviews with 2 women from Morocco and 2 women from Pakistan
14 Sept, 15.30 – 18.30	Training session – DAY 2 Agenda: 15.30 Recap study objective(s) 15.40 Research tools for focus groups (vignettes, topic guide, questionnaires): practical tips 18.00 Coordination of pilot focus groups and recruitment of participants 18.30 Close
15 and 16 Sept	Focus groups' moderators and RAs' practice: 2 pilot focus groups with 2-3 Moroccan and Pakistani women

Appendix 3 Matrices for the recruitment of participants for the SNA interviews.

AGE	-10 years living in Spain		+10 years living in Spain	
	1 – 5 years	6 – 10 years	10 – 20 years	+ 20 years
26 – 35	<p>MC06 (Khadija) TRANSCRIPT</p> <p>Age: 30 Years in Spain: 4 Migration info: Tourist visa Marital status and children: Single, with 1 daughter Origin (rural vs urban): Laaraich city Place of residence: Terrasa Education: Secondary school Occupation: Currently unemployed (before she worked in hospitality industry) Spanish proficiency: She cannot speak in Spanish</p>	<p>MC03 (Khadija) TRANSCRIPT</p> <p>Age: 26 Years in Spain: 8 Migration info: Family reunification (husband) Marital status and children: Married, with 2 sons (7 and 5 yrs) Origin (rural vs urban): Tétouan city Place of residence: Rubi Education: Secondary school Occupation: Housewife Spanish proficiency: She is taking Spanish classes (she cannot speak Spanish)</p> <p>MC04 (Jone) TRANSCRIPT</p> <p>Edad: 33 Años en España: 8 Proceso inmigración: Reagrupacion (husband) Estado Civil e hijos: Casada Origen en Marruecos: xxx Urbano Lugar de residencia actual: Terrassa Educación: University (Marruecos) Empleo: Monitora Nivel de castellano: She can speak Spanish.</p>	<p>MC11 (Khadija) TRANSCRIPT</p> <p>Edad: 28 Años en España: 11 (Llegó en 2009 con 17 años) Proceso inmigración: Reagrupacion (padre) Estado Civil e hijos: soltera y no hijos Origen en Marruecos: xxx Lugar de residencia actual: Terrassa Educación: Secondary school Empleo: Carer in a nursing home (residencia de ancianos) Nivel de castellano: She understands and speaks Spanish. Her local language is Rifeño (dialect of Amazigh)</p> <p>MC08 (Jone) IN PROGRESS</p> <p>Age: 34 Years in Spain: 11 Migration info: reagrupacion padre Marital status and children: Single Origin (rural vs urban): Place of residence: Terrasa Education: FP - turismo Occupation: Desempleada Spanish proficiency: High</p>	
36 – 50	<p>MC10 (Khadija)</p> <p>Age: Years in Spain: Migration info: Marital status and children: Origin (rural vs urban): ciudad</p>		<p>MC12 (Iman/Khadija) TRANSCRIPT</p> <p>Age: 45 Years in Spain: 15 Migration info: Family reunify. (husband) Marital status and children: Married, with 3 children</p>	<p>MC02 (Jone) IN PROGRESS</p> <p>Age: 45 Years in Spain: 29 Migration info: She migrated alone, she had relatives in Barcelona</p>

	<p>Place of residence: Mataro Education: No studies Occupation: Housewife Spanish proficiency: She cannot speak Spanish</p>		<p>Origin (rural vs urban): Tanger city Place of residence: Sant Adria de Besos, Barcelona Education: University studies Occupation: Arabic translator at the court Spanish proficiency: She speaks Spanish</p> <p>MC04 (Jone) IN PROGRESS</p> <p>Age: 38 Years in Spain: 14 Migration info: Family reunify. (husband) Marital status and children: Married, with 3 children Origin (rural vs urban): xxxx Place of residence: Terrasa Education: University studies (2 years) Occupation: Housewife. Before she taught Arabic in the Mosque in Terrassa. Spanish proficiency: She speaks bit Spanish</p>	<p>Marital status and children: Divorced, with 1 son Origin (rural v urban): Town in Nador Place of residence: Terrasa Education: Primary school Occupation: Domestic worker Spanish proficiency: She can speak Spanish</p>
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51 – 65	<p>MC05 (<i>Khadija</i>) TRANSCRIPT</p> <p>Age: 50 Years in Spain: 5 / su marido lleva tiempo aqui y les hizo la reagrupación en 2004 – Vivieron un año, 2017 Migration info: Family reunification (husband) Marital status and children: Married, with 7 children Origin (rural vs urban): ciudad Place of residence: Terrassa Education: Secondary school Occupation: Housewife Spanish proficiency: She cannot speak Spanish</p>		<p>MC07 (<i>Khadija/Iman</i>) TRANSCRIPT</p> <p>Age: 58 Years in Spain: Migration info: Marital status and children: Origin (rural vs urban): Place of residence: Terrassa Education: Occupation: Spanish proficiency: Se cannot speak Spanish</p>	<p>MC01 (<i>Jone</i>) TRANSCRIPT</p> <p>Age: 54 Years in Spain: 32 Migration info: She migrated alone with student visa. She had relatives in Barcelona Marital status and children: Married, without children Origin (rural vs urban): Kenitra city Place of residence: Zona Franca, Barcelona Education: Formacion profesional Occupation: Municipality worker Spanish proficiency: She can speak Spanish</p> <p>... (<i>Khadija</i>) INCOMPLETE</p> <p>Age: 65 Years in Spain: 32 Migration info: Family reunification (husband) Marital status and children: Married, with 8 children Origin (rural vs urban): Tetuan city Place of residence: Rubi Education: no academic education Occupation: Housewife Spanish proficiency: She cannot speak Spanish</p>
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AGE	-10 years living in Spain		+10 years living in Spain	
	1 – 5 years	5 – 10 years	10 – 20 years	+ 20 years
26 – 35	<p>PC02 (<i>Andleeb</i>) TRANSCRIPT</p> <p>Age: 27 Years in Spain: 1 Migration info: with family Marital status and children: Married with one daughter Origin (rural vs urban): Mirpur city, Kashmir Place of residence: Hospitalet de Llobregat Education: Secondary school Occupation: Housewife Spanish proficiency: Low</p> <p>PC06 (<i>Andleed</i>) IN PROGRESS</p> <p>Age: 32 Years in Spain: 3 Migration info: Reagrupación familiar (husband?) Marital status and children: Married with one daughter Origin (rural vs urban): Islamabad city Place of residence: Poble Sec, Barcelona Education: University studies Occupation: Housewife Spanish proficiency: Low</p>	<p>PC05 (<i>Jone</i>) TRANSCRIPT</p> <p>Age: 29 Years in Spain: 7 Migration info: reagrupacion marido Marital status and children: married with 2 children Origin (rural vs urban): xxx Place of residence: Hospitalet de Llobregat Education: University studies Occupation: Unemployed, housewife Spanish proficiency: High</p>	<p>PC08 (<i>Andleeb</i>) IN PROGRESS</p> <p>Age: 32 Years in Spain: 10 Migration info: XX Marital status and children: married Origin (rural vs urban): xxx Place of residence: XX Education: Secondary school Occupation: .. Spanish proficiency: Very low</p>	

36 – 50	<p>.... (Andleeb)</p> <p>Age: Years in Spain: Migration info: Marital status and children: Origin (rural vs urban): Place of residence: Education: Occupation: Spanish proficiency: Alto</p>	<p>PC07 (Jone) IN PROGRESS</p> <p>Age: 39 Years in Spain: 10.8.2015 Migration info: Marital status and children: Married with 2 children Origin (rural vs urban): Islamabad city Education: Uni – nutrition and food Place of residence: Barcelona Education: University studies Occupation: housewife Spanish proficiency: High</p>	<p>PC01 (Jone) TRANSCRIPT</p> <p>Age: 40 Years in Spain: 15 Migration info: She migrated with her husband Marital status and children: Married, with 1 son Origin (rural vs urban): Islamabad city Place of residence: Selva Mar, Barcelona Education: University studies Occupation: Cultural mediator in primary health care Spanish proficiency: High</p> <p>PC12 (Andleeb) TRANSCRIPT</p> <p>Age: 38 Years in Spain: 13 Migration info: Family reunification Marital status and children: Married with 3 children Origin (rural vs urban): Mirpur city, Kashmir Place of residence: Hospitalet de Llobregat Education: Primary school Occupation: Housewife Spanish proficiency: Very Low</p>	<p>PC03 (Jone) IN PROGRESS</p> <p>Age: 48 Years in Spain: 20 Migration info: with husband Tourist Visa Marital status and children: Married, with 3 children Origin (rural vs urban): Karachi Place of residence: Hospitalet de Llobregat Education: University studies Occupation: Housewife (volunteer Urdu, Spanish and Coran teacher in the Mosque) Spanish proficiency: High</p>
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51 – 65		<p>PC04 (<i>Sumaira/Andleeb</i>) TRANSCRIPT</p> <p>Age: 52 Years in Spain: 12 years Migration info: Family reunification Marital status and children: Married with 3 children Origin (rural vs urban): Lahore, Punjab Place of residence: Hospitalet de Llobregat Education: Secondary school Occupation: Housewife Spanish proficiency: Intermediate</p>	<p>PC11 (<i>Sumaira/Andleeb</i>) TRANSCRIPT</p> <p>Age: 59 Years in Spain: 12 Migration info: Family reunification Marital status and children: Married with 3 children (1 daughter, 2 sons) Origin (rural vs urban): Pueblo de Punjab, Pakistan Place of residence: Hospitalet de Llobregat Education: no studies Occupation: Housewife Spanish proficiency: Cannot speak Spanish, neither Catalan</p>	<p>PC08 ... (<i>Andleeb</i>)</p> <p>Age: Years in Spain: Migration info: Marital status and children: Origin (rural vs urban): Place of residence: Education: Occupation: Spanish proficiency:</p>
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Appendix 4 Focus group discussion topic guide.

INSTRUCTIONS for the moderators: How to use the FGD Guide:

The objective of this group interview is to explore barriers and facilitators to cervical cancer screening and acceptability of HPV self-sampling among Moroccan/Pakistani women living in Barcelona. In particular, we will be interested in asking questions about their knowledge, perceptions, beliefs and attitudes towards cervical cancer, as well as their prevention practices and experiences about cervical cancer screening. Additionally, we will ask some questions about their social lives and who are the people they trust for health information and advice.

- There are two levels of questions:

Primary interview questions: appear in **the left column**. They address the topics that you as the moderator must ask and encourage participants to respond and discuss. *The moderator's goal is to generate a maximum number of different ideas and opinions from as many different people.* The discussion is free-flowing. Ideally, participant comments will stimulate and influence the thinking and sharing of others. The primary questions are suggestions for getting the discussion going and you do not need to read them verbatim. Instead, you can rephrase them. During the discussion of each topic, you can use the sub-questions/probing topics in the right column to stimulate the conversation and address these sub-topics in case participants do not mention them. You can and should formulate other questions to clarify or understand relevant comments during the discussion, for example, the 'whys'. It is important you to be engaged with the conversation, make all women feel comfortable and make sure all of them participate equally.

Sub-questions/Probing topics: are in **the right column**. These are to assist and encourage further discussion with the participants in case they are providing little information. It's not a requirement to cover every probe. Which probes you may or may not ask will depend on what has already been discussed.

With permission from the participants, **Moderator 1** should take notes and these notes should be labelled with initials or participant's ID. You will take notes in a separate notes form or sheet, where you will also insert your initials, as well as the date, where the group interview is taking place and the start and end of the FGD. **Moderator 2** should facilitate the discussion.

Before starting the FGD, ensure the participants have provided written informed consent and before the end of the FGD ensure the participants filled in the sociodemographic questionnaire.

Moderator 1:

Moderator 2:

Date:

Place where the FGD takes place:

FGD Start Time:

FGD Stop Time:

FOCUS GROUP DISCUSSION GUIDE

INTRODUCTION

10 minutes

Thanks for coming today. Today's group interview has **two goals**: 1. to explore the challenges and facilitators you may face to access and use public health services in Barcelona and, in particular, cervical cancer screening program, and 2. to understand your preferences to undertake a vaginal smear (clinician vs self-sampling).

Before we start the discussion, we would like to give you a short introduction of the study and if you accept to participate in the focus group, we will ask your **written consent** and to sign off a confidentiality agreement. [*Oral explanation of the participant information sheet and study objectives – summary in page 1 of this guide*]

Please, read carefully the written consent form, as well as the confidentiality agreement, and sign them off. If you have any questions, feel free to ask. We will give a copy of all these documents for you to read them again, if you need it.

(...)

Thanks for accepting to participate in this study. I will give you now a short explanation on **how a focus group works**. This is an informal discussion, all views are welcome and it is expected to be an interactive session. If you have any question about this session and the research, please, you can ask now or at any time during the discussion.

There are only a few basic rules to keep in mind while participating today:

- Everyone is expected to be an active participant.
- There are no “right” or “wrong” answers.
- Speak freely but remember not to interrupt others while they are talking.
- Audio recording and note taking is for research purposes only and will be used for analysis. Names are not attached to the notes, instead we will use codes to ensure anonymity.
- All feedback today will remain confidential and anonymous. In order to maintain confidentiality, I just ask that anything that is said during our session is not repeated outside of our session

The session will have 2 parts with a little break to go to the toilet and we will also have some refreshments during the break, but you can help yourself tea or water during the session.

I would like to start this focus group with a brief round of **introductions**. We can start with the research team (...). Now I will ask you to introduce yourselves and let us know how long have you been living in Spain/Catalonia.

EXPERIENCE WITH THE CATALAN PUBLIC HEALTH SYSTEM

5 minutes

<p>1. What is the perception of the Catalan health system within your community compared to the health system in your country?</p>	<p><i>-For example, how easy is to get an appointment with a doctor? Are there flexible schedules?</i></p> <p><i>-How much satisfied are you with the health services provided? What would you improve?</i></p> <p><i>- Are there specific barriers that women from Morocco/Pakistan face when they go to the doctor here in Barcelona?</i></p>
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PERCEPTIONS AND ATTITUDES ABOUT CANCER IN GENERAL

5 minutes

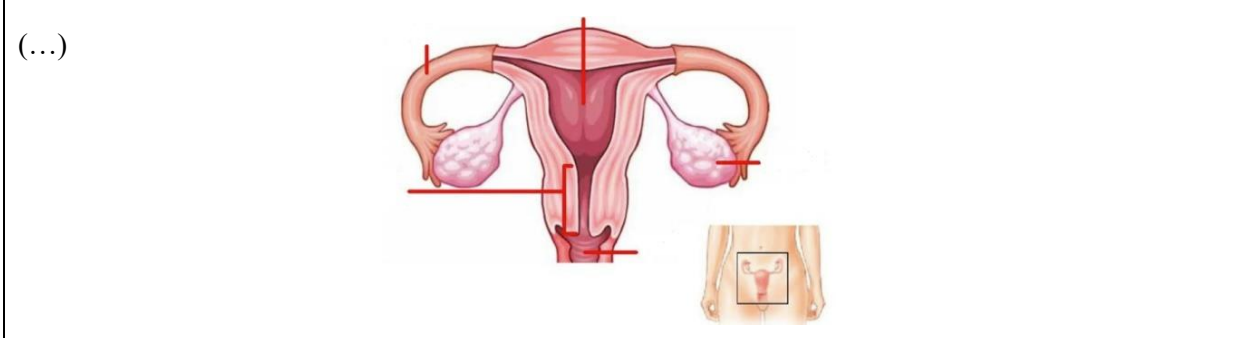
Vignette 1 Fatima is a 41 year old woman, from Morocco/Pakistan who has been living in Barcelona for more than 10 years. She is married and she has 3 children aged 8, 10 and 11 years old. She was diagnosed with cancer three months ago.

<p>2. With whom do you think Fatima should share her news about her disease and how do you think people in her community will react and feel when they learn about it?</p>	<p><i>-What do people in their community know about cancer?</i></p> <p><i>-Will people in her community talk naturally about cancer or will prefer to avoid this type of conversations? Why?</i></p> <p><i>-In which context do you think Fatima and the people in her community will talk about cancer-related topics?</i></p> <p><i>-¿What do you know about cancer?</i></p>
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KNOWLEDGE, PERCEPTIONS AND ATTITUDES ABOUT CERVICAL CANCER

15 minutes

Now, we are going to focus on our reproductive and genital organs. To do so, we are going to do a quick exercise. I will give you a page with a picture of the female reproductive system and you will need to place the right number in each of the 5 parts of our reproductive system (vagina, ovary, Fallopian tube, uterus, cervix). (See material 1)



Now we are going to share where we placed each of the parts of the **female reproductive system**. Can someone tell us where is the cervix? (*Ask about each part*)

Vignette 2 Fatima was diagnosed with cervical cancer.

<p>3. What do you know about this type of cancer?</p>	<p>- Where and what did you hear about this type of cancer? -Causes and symptoms? Is a fatal or curable disease? How we can prevent it?</p>
<p>4. Do you think there is something that can make a woman, like Fatima, be at higher risk to developing this cancer than other women?</p>	<p>-Age -Smoking -Sexual activity <i>*Ask about HPV and its association with cervical cancer</i> -Have you ever heard about this virus? Do you know someone who has had this virus? -Do you know how this virus is transmitted? -Do you think it is transmitted through sexual relationships? - Do you think it is a sexual transmitted infection? -What do you think about the link between cervical cancer and a sexually transmitted infection?</p>
<p>5. What do you think are the main concerns of Fatima about her cervical cancer?</p>	<p><i>Some examples:</i> -Fear to death -Dependency of her children -Stigma related to cancer -Stigma related to infertility -Side effects due to the treatment/disability</p>
<p>6. What do you think Fatima could have done to prevent her cervical cancer?</p>	<p><i>Some examples:</i> -Get screened for cervical cancer. -Go to the doctor once she had the first symptom. -Use protection in her sexual relationships. -etc.</p>

KNOWLEDGE, PERCEPTIONS AND EXPERIENCES ABOUT CERVICAL CANCER SCREENING

15 minutes

Vignette 3 Fatima felt healthy. He had no obvious symptoms. After having her last child 8 years ago, she did not visit a gynaecologist again, nor did she have a cytology.

<p>7. When and why do women like Fatima and you usually go to the gynaecologist or midwife?</p>	<p><i>Some examples:</i></p> <p><i>Pre- and post- natal care; fertility problems; family planning, etc.</i></p>
<p>8. Could you tell me what is a cytology and why it is done and to whom?</p>	<p><i>-Can someone give us details on how is the procedure of this test?</i></p> <p><i>-Why is it important? For whom?</i></p>
<p>9. Do you know other women like Fatima who have ever undertaken a cytology here in Catalonia or in your country? And you? Why did you do it and how was your experience?</p>	<p><i>-Was it painful, embarrassing? Didn't you understand for what the doctor was doing that test?</i></p> <p><i>-Any difference between your experience in Spain and in your country?</i></p>
<p>10. To what extent do you think Fatima's religion might have influenced the fact that she did not go to a gynaecologist appointment in such a long time and did not undertake any check-up?</p>	<p><i>-Do you think her religion might prevent her to be attended by a male gynaecologist?</i></p> <p><i>-Do you think her religion might prevent her to undertake specific tests or vaginal explorations?</i></p>

BARRIERS & FACILITATORS TO CERVICAL CANCER SCREENING

20 minutes

We are going to finish this first part of the discussion before the break talking about the barriers that might prevent women like Fatima to attend a gynaecologist appointment.

To do so we will participate in a practical exercise. We are going to try to respond all together the following question:

Why do you think Fatima did not go to the gynaecologist for such a long time and she did not undertake a cytology or got screened for cervical cancer?

We will have 5 minutes to write in post-its your own ideas about why a women like you might not go to a gynaecologist appointment to get screen for cervical cancer or undertake a cytology. We will paste the post-its on the flip-chart.

Once we have all your ideas on the flip-chart, I will give you x cards with different statements describing an attitudinal or a barrier that might prevent you from going to gynaecologist appointment and to cervical cancer screening, in particular. The statements will include your ideas and new ones.

Once you had the cards, you will be asked to rank each of the barriers to cervical cancer screening, piling them according to their relevance based on your opinion and experience, and lining up the cards

from most to least relevant. You will have three piles: 1. “Very relevant”, 2. “Less relevant” 3. “No relevant”.

1. **I never heard about cervical cancer and/or screening** (Hilverda et al 2021; Chan and So 2017, Vahabi and Lofters 2016; Addawe et al 2018; Gele et al 2017)
2. **I don’t really have time to do this test; I have other priorities, such as taking care of my children and work** (Addawe et al 2018 ; Grandahl et al 2012)
3. **I’d rather not know if I have cancer** (Marlow et al 2015, Hamdiui et al 2022, Addawe et al 2018)
4. **I have not symptoms; I don’t need to be screened** (Marlow et al 2015, Addawe et al 2018; (Gele et al 2017; Raymond et al 2014)
5. **I am not at risk to cervical cancer as I am in a marital relationship** (Chan et al 2019)
6. **I need to keep my virginity before I got married, so I cannot be screened** (Szarewski et al 2009; Addawe et al 2018)
7. **Cancer is God’s wish, there is nothing you can do** (Hamdiui et al 2021; Gele et al 2017)
8. **I would never go to an gynaecology examination with a male doctor; it is against my religion** (Hamdiui et al 2021; Hilverda et al 2021; Szarewski et al 2009, Vahabi and Lofters 2016; Addawe et al 2018)
9. **I am shy to do such test, it would be too embarrassing for me** (Hamdiui et al 2021; Hilverda et al 2021; Szarewski et al 2009, Vahabi and Lofters 2016; Addawe et al 2018)
10. **I am scared about gynaecological examinations; I heard it is painful** (Szarewski et al 2009; (Gele et al 2017; (Marlow et al 2015)
11. **I don’t participate in the screening, because I don’t understand the doctor’s language** (Addawe 2018, Grandahl et al 2012; Gele et al 2017)

11. These are the most relevant barriers that you have mentioned. What do you think about this barrier?

12. Is there anything we could do to overcome these important barriers?

BREAK (10 minutes)

BRIEF DEMONSTRATION OF HPV SELF-SAMPLING AND ITS USE

5 minutes

Vignette 4 After 8 years, Fatima visited the gynaecologist accompanied by her sister because she had some blood loss (vaginal bleeding). During the appointment, the doctor proposed her to undertake a test to detect the Human Papillomavirus, which is the necessary cause for cervical cancer. He offered her two options: collect the sample herself at home with a self-sampling device or have the sample collected by a health professional at the health centre.

HPV SELF-SAMPLING ACCEPTABILITY AND SELF-EFFICACY

10 minutes

13. What do you think about undertaking a test to detect a virus which is transmitted through sexual relationships? How this test would be accepted in your community?

14. What do you think Fatima’s husband and people in her community may think about using this device for women to collect the sample themselves at home, instead of going to a health professional?

INTENTION OF USING HPV SELF-SAMPLING; ADVANTAGES AND DISADVANTAGES AND SOCIAL SUPPORT NETWORKS

10 minutes

15. Which screening method do you think Fatima chose? Why? (Optional – depending on timing)

16. What are the advantages and disadvantages of each option offered to Fatima?

17. How confident would you feel if you would decide to use the HPV self-sampling? Whom would you turn to for information and advice if you would need it?

INVITATION TO CERVICAL CANCER SCREENING

5 minutes

18. How would you like to be invited to a cervical cancer screening?

Some options:

-Through a letter posted to my home

-Text message

-WhatsApp or similar automated messages.

-In a community workshop with a health professional

-In the health centre, through a health professional (my GP or midwife)

-Other ways (specify)

19. And if you would decide to use the HPV self-sampling, where would you like to receive and return it?

-For example, at home, in the pharmacy, in a health centre, in a community space, other ways (specify)

EXIT QUESTION

5 minutes

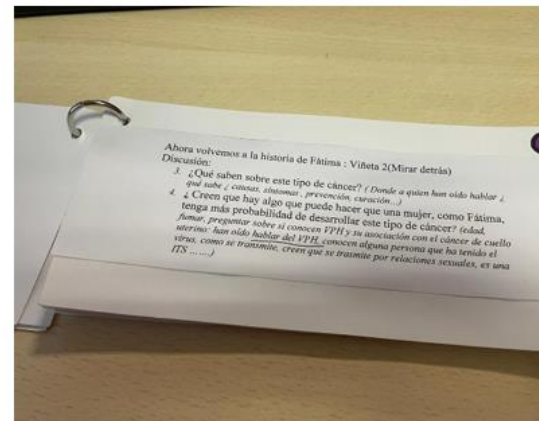
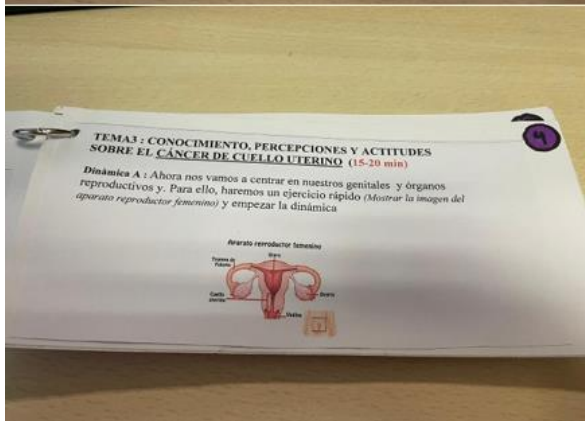
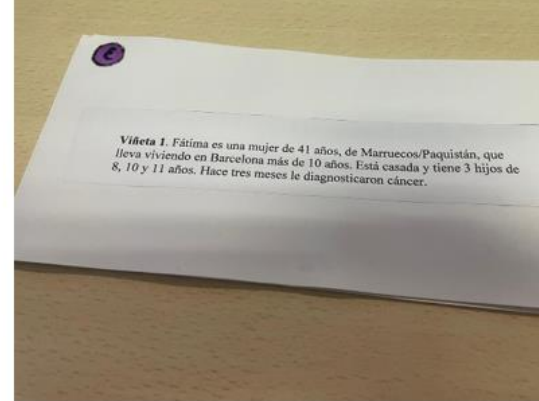
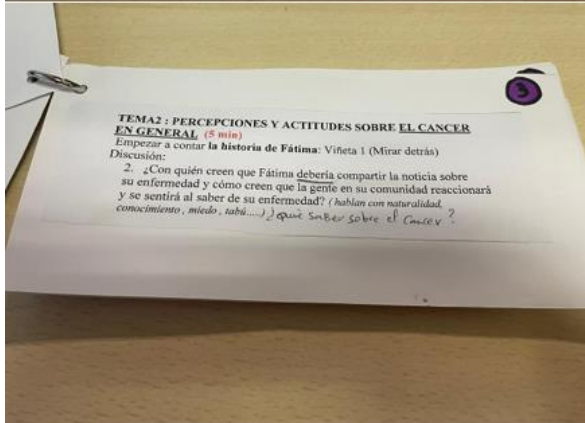
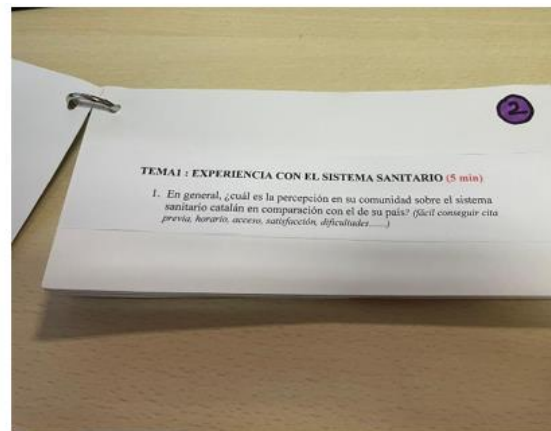
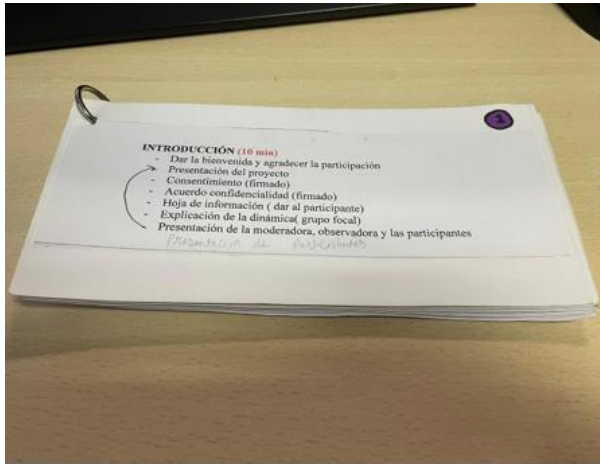
Vignette 5 Fatima decided to use the self-sample device. The test was positive (it seems that she had an infection caused by the Human papillomavirus) and a health professional performed a cytology to check if there was a lesion on the cervix. After various tests, Fatima was diagnosed with cervical cancer.

20. Is there anything else that you would like to say about Fatima's history and/or cervical cancer screening?

- **Help participants to fill in the socio-demographic questionnaire.**
- **Offer and give participant the HPV self-sampling kits. Explain that it is a trial and they will not receive the test results, but you can get an appointment for them with the gyne, and give brief explanation of the acceptability questionnaire.**

Thank you very much for taking part in this study!

Focus group discussion topic guide adapted by the moderators to use in the sessions.



FOR HEALTHCARE PROVIDERS

1. Cultural awareness and competence of health practitioners

- 1.1. What is your role in the health center?
- 1.2. How long have you been working in your current position?
- 1.3. Tell me about your personal experience working with patients in a multicultural environment.

Prompts

What are the main challenges?

How do you deal with the challenges you face?

How is your relationship with your patients, especially, those from other countries?

Are you trained or do you take any specific action to improve your relationship with these patients?

What factors/skills do you think could improve cross-cultural healthcare?

2. Support available for immigrants to access the Catalan health system

- 2.1. What is the support available for these multi-cultural patients to access and use the Catalan health services?
- 2.2. In your opinion, what additional measures could be implemented to improve access and use of health services among immigrant women?

3. Immigrants' preventive health behaviours

- 3.1. Do you perceive differences in how different types of patients seek healthcare services? Could you, please, give some examples.
- 3.2. Does this bring any specific challenge?
- 3.3. Any other challenges working with different ethnic backgrounds?

4. Sexual and Reproductive health service delivery for Moroccan and Pakistani women

Let's focus now on sexual and reproductive health services.

- 4.1. What are the main challenges of health practitioners in delivering SRH services to Moroccan and Pakistani women?
- 4.2. How do you deal with these challenges?
- 4.3. What is your perception about these patients' health seeking behaviours? When and how do they seek SRH care? Do they attend gynaecology appointments less frequently than other women? Why?
- 4.4. According to your experience, do Pakistani and Moroccan women have specific needs, preferences and attitudes when attending a gynaecologist appointment? Give me details, please.

Prompts:

*For example, do they attend gynaecologist appointments for contraception services?
Or only for anti & post-natal care?*

Do you think the fact that they may go accompanied can be a barrier or prevent them from asking questions, express some concerns or be offered specific services (e.g. contraception)?

5. Health prevention practices among Moroccan and Pakistani women

5.1. From your experience, to what extend do Moroccan and Pakistani women self-care and what kind of health prevention practices do they adopt in their daily lives?

Prompts

Do they go to the doctor for regular health check-ups?

Do they care or ask you about how to have a healthy lifestyle?

Do they follow health professionals' recommendations or do they trust more traditional medicine from their countries?

5.2. In your opinion, to what extend are they aware of the available health prevention services in Catalonia?

6. Knowledge and attitudes towards cervical cancer

Let's focus now on cervical cancer.

6.1. To what extend do you think Pakistani and Moroccan women are at risk of cervical cancer?

6.2. From your experience, what do these women know about sexually transmitted infections? Do they know that they can be prevented with contraceptives?

6.3. In your view, to what extend these women know that a sexually transmitted virus (Human Papillomavirus) is the necessary cause of cervical cancer?

6.4. Do you think these women know that cervical cancer is preventable? Why?

7. Barriers to cervical cancer screening

7.1. Do you perceive any difference among Moroccan and Pakistani women's participation in cervical cancer screening compared to other patients? If so, in which sense? Why?

Prompts:

Do you think they prioritize this service or are afraid of it? Of perhaps, they don't know about it?

7.2. In your opinion, what are the main barriers to cervical cancer screening among these patients?

7.3. How could we overcome these barriers?

8. Knowledge and acceptability of HPV self-sampling

8.1. As a health professional, what do you know about HPV self-sampling?

8.2. Are you familiarized with the cervical cancer screening protocols? If so, do you adhere to these protocols?

8.3. What are the attitudes of Moroccan and Pakistani patients to genital examinations, in general?

8.4. In your opinion, what are the relative levels of comfort and confidence with their own bodies?

8.5. From your experience working with these patients, to what extend do you think Moroccan and Pakistani women would accept and feel comfortable taking a vaginal smear themselves in their homes?

8.6. In your opinion, what would be the main issues, if any, in implementing HPV self-sampling for cervical cancer among these patients from Morocco and Pakistan?

9. Facilitators to cervical cancer screening

As you will know, the cervical cancer screening program in Catalonia is transitioning from opportunistic to an organised population-based program. All women between 30 and 65 years old will be invited to get screened. There are various pilot projects on going to assess the transition from cytology to HPV-based test, and from clinician-based to self-sampling collection. In this context:

9.1. How could we increase participation of Moroccan and Pakistani women in cervical cancer screening programmes in Catalonia?

9.2. From your view, what approach would be the best to reach these two communities of women and invite them to get screened for cervical cancer? For example, by phone text, community outreach.

9.3. What impact do you think the introduction of HPV self-sampling will have on these women populations?

SOCIODEMOGRAPHIC DATA OF KEY INFORMANTS

Age/Date of Birth

Gender

Country/region of origin

Marriage status

Education

Years of experience

Years in your current position

% immigrant patients visited weekly

% Moroccan & Pakistani patients visited weekly

FOR COMMUNITY HEALTH AGENTS AND CULTURAL MEDIATORS

1. Moroccan/Pakistani women immigrants' main concerns
1.1. What is your role in the health center? 1.2. How long have you been working supporting Moroccan/Pakistani women? 1.3. What type of support do you provide to these women? 1.4. Please, tell me about your experience working with these women 1.5. From your experience, what are the main challenges these women face in their daily lives when they first arrived in Barcelona? And after a few years living here?
2. Support available for immigrants to access and use the Catalan health system
2.1. What is the support available for these multi-cultural patients to access and use the Catalan health services? 2.2. In your opinion, what additional measures could be implemented to improve access and use of health services among immigrant women?
3. Moroccan/Pakistani women's health seeking behaviour
3.1. When and how do Moroccan/Pakistani women seek care in Barcelona? For example, do they go regularly to the GP or use more often the emergency services?
4. Provision of Sexual and Reproductive health services
<i>Let's focus now on sexual and reproductive health services.</i> 4.5. What is your perception about these patients' health seeking behaviours? Do they go to gynaecology appointments less frequently than other women? Why? 4.6. When and how do they seek SRH care? Prompts: <i>-For example, do they attend gynaecologist appointments for contraception services? -Or only for anti & post-natal care?</i> 4.7. Why do you think women from Morocco and Pakistan might avoid either going to a gynaecologist entirely or avoiding a vaginal examination? 4.8. According to your experience, do Pakistani and Moroccan women have specific needs, preferences and attitudes when attending a gynaecologist appointment? Give me details, please. Prompts: <i>-For example, do they ask for female gynaecologists rather than males? -Do they go alone or accompanied by someone? Whom? -Do you think the fact that they may go accompanied can be a barrier or prevent them from asking questions, express some concerns or be offered specific services (e.g. contraception)?</i>
5. Health prevention practices among Moroccan/Pakistani women
<i>Let's talk now about health prevention practices in your country.</i> 5.1. What do you understand by health prevention?

5.2. In your opinion, to what extent do Moroccan and Pakistani people self-care? And what kind of health prevention practices do they adopt in their daily lives? Do you see any differences between women and men?

Prompts

-Do they go to the doctor for regular health check-ups?

-Do they care or ask you about how to have a healthy lifestyle?

-Do they follow health professionals' recommendations or do they trust more traditional medicine from their countries?

5.3. In your opinion, to what extent are they aware of the available health prevention services in Catalonia?

6. Knowledge, beliefs and experiences about cancer, cervical cancer, HPV and screening

Let's focus now on cervical cancer

6.1. What are the attitudes of people in Morocco/Pakistan about cancer?

6.2. Does your country have in place cervical cancer prevention programmes? If so, tell me about these; are opportunistic or population-base? Are they free-of-charge?

6.3. To what extent do you think Pakistani and Moroccan women are at risk of cervical cancer? Or do you think Pakistani/Moroccan women have the same risk of cervical cancer than other women in Spain?

6.4. From your experience, what do these women know about sexually transmitted infections? Do they know that they can prevent some STI with some of the contraceptive methods?

6.5. In your view, to what extent these women know that a sexually transmitted virus (Human Papillomavirus) is the necessary cause of cervical cancer?

6.6. Do you think these women know that cervical cancer is preventable? Why?

6.7. How do you think these women would react if they are offered a test to detect a sexually transmitted virus (HPV)?

6.8. Let's talk about your personal experience. Have you ever undertaken a Pap smear in your country? And in Spain? Tell me about these experiences (any difference between them, any preference?)

7. Barriers to CC screening

7.4. Do you perceive any difference among Moroccan and Pakistani women's participation in cervical cancer screening compared to other patients? If so, in which sense? Why?

Prompts:

-Do you think they prioritize this service or are afraid of it? Of perhaps, they don't know about it?

7.5. In your opinion, what are the main barriers to cervical cancer screening among these patients? Why do they participate less frequently?

7.6. How could we overcome these barriers?

8. Knowledge and acceptability of HPV self-sampling

- 8.7. What do you know about HPV self-sampling?
- 8.8. What are the attitudes of Moroccan and Pakistani patients to gynecological examinations?
- 8.9. In your opinion, what are the relative levels of comfort and confidence with their own bodies?
- 8.10. From your experience working with these patients, to what extent do you think Moroccan and Pakistani women would accept and feel comfortable taking a vaginal smear themselves in their homes?
- 8.11. In your opinion, what would be the main issues, if any, in implementing HPV self-sampling for cervical cancer among these patients or invite them to self-sampling to detect HPV?

9. Facilitators to cervical cancer screening and

As you will know, the cervical cancer screening program in Catalonia is transitioning from opportunistic to an organised population-based program. All women between 30 and 65 years old will be invited to get screened. There are various pilot projects on going to assess the transition from cytology to HPV-based test, and from clinician-based to self-sampling collection. In this context:

- 9.4. How could we increase participation of Moroccan and Pakistani women in cervical cancer screening programmes in Catalonia?
- 9.5. From your view, what approach would be the best to reach these two communities of women and invite them to get screened for cervical cancer? For example, by phone text, community outreach.
- 9.6. What impact do you think the introduction of HPV self-sampling will have on these women populations?

SOCIODEMOGRAPHIC DATA OF KEY INFORMANTS

Age/Date of Birth

Gender

Country/region of origin

Marriage status

Education

Years of experience

Years in your current position

Protocol for social network data collection (Network Canvas)

Participant ID:

Interview place:

Researcher and/or interviewer

1. Questions about Ego (participant)

Thank you for giving your consent to be interviewed. I would like to start this interview asking you some personal questions.

1.1. What is your date of birth? dd / mm / yyyy

1.2. What year did you migrate to Spain?

1.3. How many people do you live with? I live alone / 1 / 2 / 3 / 4 / 5 or more / Prefer not to answer

1.4. Which language(s) do you speak most often at home? (you can select more than one)

Spanish / Catalan / Arabic-Darija / Urdu / English / French / Other (specify) / Prefer not to answer

1.5. What is your marital status? Single / Married or living with my partner / Separated / Divorced / Widowed / Other (specify) / Prefer not to answer

1.6. Do you have children? Yes / No / Prefer not to answer

1.7. If so, how many children do you have? 1 / 2 / 3 / 4 / 5 or more / Prefer not to answer

1.8. Tick the boxes in relation to your education (you can tick more than one):

No academic education / Primary school / Secondary school / University studies / Vocational training / Koranic school / Other (specify) / Prefer not to answer

1.9. Are you employed?

Yes, I am employed (full-time, part-time, self-employed) / No, I am unemployed (housewife) / Informal employment / Retired / Prefer not to answer

1.10. Can you give an estimate of your annual household income? < €12,000 / € 12,001 – €20,000 / € 20,001 – 30,000 / € 30,001 – 40,000 / > €40,001 / I don't know / Prefer not to answer

1.11. Do you have public health insurance in Catalonia? Yes / No / Prefer not to answer

1.12. If you have ever attended a gynaecologist appointment, have you ever undertaken a cytology?
Yes / No / Don't know / Prefer not to answer

1.13. If you have ever undertaken a cytology, how long is it since the last time that you did so?

Less than 1 year / between 1 and 3 years / between 3 and 5 years / for more than 5 years / I don't know / Prefer not to answer

1.14. Would you say you are a religious person?

Very religious / Somewhat religious / Very little / No religious at all / Prefer not to answer

1.15. Do you identify yourself as a Muslim person? Yes / No / Prefer not to answer

2.Name Generator I – Personal Networks

Now we are going to map your personal network and we would like to ask you to list the people with whom you interact regularly in your life. You don't need to give me their names, you can use their initials or a nickname, if you prefer. If two persons have the same name we will need to use their surname initials or distinguish them in another way.

Please, list people whom you know by name or by sight, and with whom you had some contact in the past 2 years either face-to-face, by phone, or by the Internet and whom you could still contact if you had to, in the following social contexts of your life.

Per each question there may be a few people or none that fit the description. You can mention the same person more than once, in case the person fit more than one description. There is not a correct number of people per each question.

2.1. We can start by your family circle. These can be your own family or your spouse's family members, and they can live either in Barcelona, other Spanish region or abroad.

2.2. Let's continue with your friends. Do you have any friend or friends to whom you are most often in contact (they can live in Spain or abroad).

2.3. Think about your neighborhood. Who are the people with whom you talk a little more and you can contact if you need to? For example, when you go to the shop, to the "casal" or your children's school.

2.4. Let's talk about your religious practice, do you go to any religious center in Barcelona? In this context, do you have any person who is more special or closer to you?

2.5. In your free time, do you participate in any educational or leisure activity, such as language classes, sewing or you are a member of an association? Do you have any person with whom you like to spend more time in these activities?

2.6. Let's think about your workplace. Is there anyone in this context you know a little better, with whom you talk a little more or you used to work with and you are still in contact?

3.Name Generator II – Health information and advice networks

Now I will ask you questions about the people with whom you talk about health. These may be people you already mentioned or other people, such as your doctor, a intercultural mediator or someone who lives abroad.

- 3.1. Whom would you turn to for information and advice about an important problem or decision related to women's health, such as having children? (Why these people?)
- 3.2. Whom would you turn to for information and advice about an important problem or decision related to women's health, such as symptoms of a STI? (Why these people?)
- 3.3. Whom would you turn to for information and advice to decide whether or not to undertake a cytology or get screened for cervical cancer? (Why these people?)
- 3.4. Whom would you turn to for information and advice about how to use a new device to collect yourself a vaginal sample at home for cervical cancer screening? (Why these people?)
- 3.5. Is there any other relevant person that you didn't mention?

4.Alter's attributes and composition of personal networks

I will ask you now some personal questions about the people you mentioned and the type of relationship you have with them.

- 4.1. Is this person female or male? Yes/No
- 4.2. What type of relationship do you have with this person?
Sons-daughters / Husband-Partner / Father-Mother / Sister-Brother / Other close relatives / My husband-partner's family / Friend / Acquaintance (specify)
- 4.3. What is the education of this person? No School / Primary school / Secondary school / Vocational training / University degree / Koranic school / Other (specify)
- 4.4. In which age range is this person? Less than 30 years / between 31 and 40 years / between 41 and 50 years / less than 50 years
- 4.5. Where is this person from?
From the country I was born / From Spain / From another country / I don't know
- 4.6. Where does this person live?
In the country I was born / In Spain / In another country / I don't know

4.7. How often do you talk with this person?

Daily / weekly / monthly / less than once a month

4.8. How do you usually communicate with this person?

Face to face / phone / WhatsApp or similar / email / letter

5. Conversations about cancer and cervical cancer screening

Now I will ask you questions about the people to whom you have ever talked about cancer related topics.

5.1. Have you ever talked about cancer with this person? Yes/No

5.2. Do you think this person think you should undertake a cytology or get screened for cervical cancer? Yes/No (**If you are not sure or you don't know the answer, select the option 'NO'*)

5.3. Have this person ever recommended you to undertake a cytology or get screened for cervical cancer? Yes/No

6. Female contacts' cervical screening status

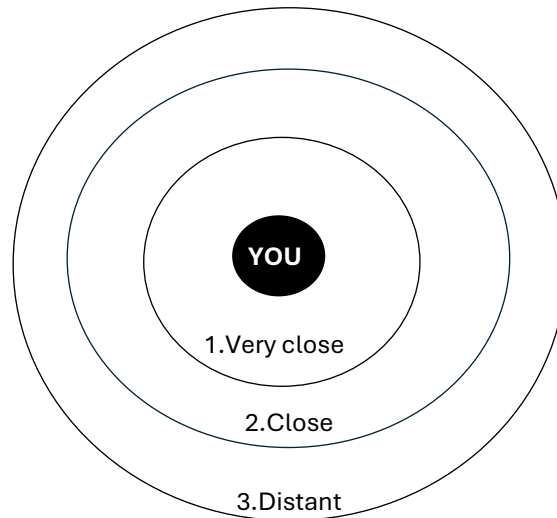
Now, I will ask you only about your female contacts and cervical cancer screening.

6.1. Do you think this person has ever undertaken a cytology or cervical cancer screening? Yes/No (**If you are not sure or you don't know the answer, select the option 'NO'*)

7. Strength of relationships and links between contacts (Sociogram)

Now, I am going to place all the people you mentioned on a map called sociogram. This is a sociogram. You are the central point and the circles surrounded you represent the people who are part of your social network or you interact with in your life. They may or may not be close to you (emotionally speaking).

- 1. The inner circle is for "people to whom you feel so close that it is hard to imagine life without them" (for example, for me it would be my mum).*
- 2. The middle circle is for "people to whom you may not feel quite that close but who are still important to you" (for example, for me it could be a close friend).*
- 3. And finally, the third outer circle is for "people who are not so close emotionally, but they are somehow relevant enough to be in your social network" (for example, for me it could be a workmate or my GP).*



7.1. Please, place each person of your social network in the corresponding circle according to how close emotionally you feel towards them.

To end, I will ask you about the connections between the people you mentioned.

7.2. Please, can you add an arrow between the people whom know each other. By “know each other” we mean that they might contact, meet or talk to each other even if you are not there.

Appendix 7 Semi-structured interview topic guide.

Semi-structured interview topic guide with Moroccan and Pakistani women

Participant ID:

Participant place of residence:

Interview place:

Researcher and/or interviewer

MIGRATION, SOCIAL SUPPORT AND SOCIAL NETWORKS

With your social network map in front of us, I will ask you some more questions about your contacts and health.

1. How does change your network of contacts before and after migrating to Spain? For example, is your current social network very different than your social network back in your country?
2. Looking at your contacts in the sociogram, who are the most supportive people in your life?

BARRIERS TO ACCESS HEALTH CARE SERVICES AND HEALTH SEEKING-BEHAVIOURS

Let's continue talking about your health.

5. When and why do you usually go to the doctor?

Prompts

-Do you go to the doctor as frequently as you did in your country?

-What do you think about the health system here? How are the doctors?

-For example, when do you go to the emergency services? Only when you feel very sick?

-Do you usually use traditional medicine from your country before going to the doctor? Give me details.

6. What are the main barriers you confront when you need to access health services?

HEALTH PREVENTION AND SOCIAL SUPPORT NETWORKS (conceptualization of prevention, social norms)

7. How much would you say you self-care and what do you do to take care your health?
8. How much do your family, for example, your husband or daughters, care about your health? How supportive are they? Give me some examples, please.
9. What kind of recommendations do your family and friends give you about health in general? And in particular, do they encourage you to do regular check-ups?

Prompts

Do they give you religious or spiritual advice?

Do you keep healthy diet, exercise, etc.?

10. Why do you think people do health regular check-ups?
11. In your country, do people do regular health check-ups?
12. If you would know that some diseases have not symptoms, would you do check-ups more regularly?
13. What do you think about doing tests to detect early a disease, like cancer? Are they useful, do you think they can prevent cancer?
14. What do you think your family and friends think about prevention programmes?

CONVERSATIONS ABOUT CANCER AND CERVICAL CANCER (awareness and knowledge)

Let's look at your social network again.

15. You said that you talked about cancer with a few people (**question 5.1.**) How do you think your family and friends feel when they hear the word 'cancer'?
16. Do you and the people in your family and friend circles talk naturally about cancer or you try to avoid this kind of conversations? Why?
17. Is there anyone in your family and friend circles whom has ever experienced cancer? YES – NO

Prompts

If yes, please, could you tell how many and how did you know about it?

Let me know a little bit more about these cases. How did you support them?

18. Before we said that a 'cytology' test is to detect cervical cancer. Is there any woman in your family or friend circles whom has ever experienced cervical cancer?

YES – NO

Prompts

How many? Can you share your experience? How did you know? Did they share it with other people? What was your reaction? How did you support them?

CERVICAL CANCER SCREENING AND SOCIAL SUPPORT NETWORKS (barriers/facilitators)

Let's focus on women's health issues.

19. Before you said that you have/have never got screened for cervical cancer or undertaken a cytology (**question 1.12 and 1.13**),
 - If **NOT or LONG TIME AGO**, why?
 - If **YES**, did you get screened in Barcelona and/or your country? **Tell me about your experience.**

Prompts

Whom did/does arrange the appointment with the gynecologist for you?

What was the reason of the visit(s)?

Did you need a translator? With whom did you go?

How do you remember the last appointment? Was the doctor female or male? How supportive, sensitive he/she was?, was it painful, embarrassing?

Is there any difference between here and your country?

20. If you need help with the Spanish language, whom you prefer to go with or assist you when you go to a gynecologist appointment,? Why?
21. Has an intercultural mediator ever helped you during a gynecologist appointment? How was it? (e.g. helpful, do you prefer someone else?)
22. Does your family, for example, you husband has a say in decisions that affect your health and, in particular, your sexual and reproductive health? Let me know how do they get involved in the decision-making.

Prompts

Do they tell you what you should do?

Do they make decision for you?

23. Do you know any woman in your community who needs to ask permission to her husband to go to the doctor, to the gynecologist? Could you share the case with me, please?
24. Why do you think women like you might avoid to go to the gynecologist and, in particular, to undertake a cytology? Think about your experience or a relative´s or friend´s experience.
25. Do you think religion could affect the decision about going or not to the gynecologists? Some people believe that religion does not allow women to be examined by a male doctor, what do you think?
26. How would you like to be invited for a cervical cancer screening? Through a letter / SMS / after an informative event in your community / through a health professional / Others (specify)

CONVERSATIONS AND KNOWLEDGE ABOUT HUMAN PAPILLOMAVIRUS (HPV)

27. Have you ever heard or talked with someone in your social network about the Human Papillomavirus (HPV)? With whom?

Prompts

For example, in your children school?

28. Now that you know what is the cause of the cervical cancer, how likely do you think you would develop cervical cancer? Why?

Prompts

Do you think the religion is a protecting factors against these diseases in your community? Why?

For example, do you think men in your communities could have sex before marriage?

29. Would you do this test to detect this sexually transmitted virus (HPV) or do you think it is not relevant or it would not be accepted in your community?

SCREENING PREFERENCES AND HPV SELF-SAMPLING ACCEPTABILITY

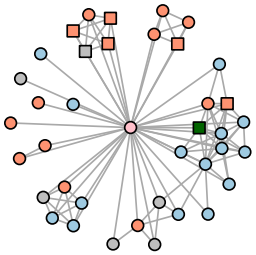
SHORT DEMONSTRATION OF HPV SELF-SAMPLING DEVICES

We are finishing this interview with a few more questions about this device. This is a HPV self-sampling (show instructions, illustrations). Now women have the possibility of taking a vaginal smear themselves at home for cervical cancer screening. This self-sampling device, in particular, is to take a vaginal smear that allows to detect the HPV, which is the necessary cause of cervical cancer.

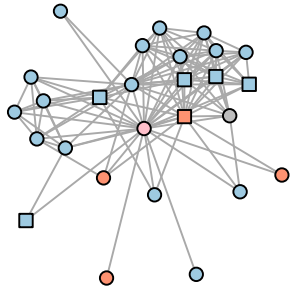
30. If you would be offered to be screened for cervical cancer, what would you prefer: to go to a clinician or to do it yourself at home? Why?
31. In your opinion, what do you think are the advantages and disadvantages of using this device?
32. If you would decide to use it, how confident would you feel to use it?
 - I would be worried about use it correctly
 - I would feel confident with appropriate instructions
33. Do you think this device (self-sampling) is the solution for those women who do not go to the gynaecologist because of fear, shyness or do not want to be examined by a male doctor?
34. And if you opt to use the self-sampling device, where would you like to receive and return this device? Why? (In a health center /receive it at home and return to the pharmacy / receive and return it through a community agent)
35. What about an information campaign about cervical cancer screening? How would you like this to be presented? (In a community event with other women / through a video / with illustrations / other ways)
36. Would you like and would you feel yourself confident to become a 'champion' or inform other women in your community about cervical cancer screening?

Appendix 8 Network graphs of the 22 Moroccan and Pakistani participants, length of stay in Spain and CC screening status.

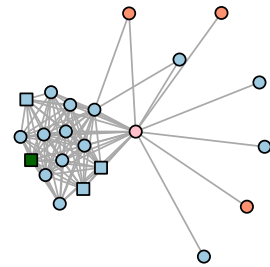
**MC01, 32 yrs Spain,
adequate screened**



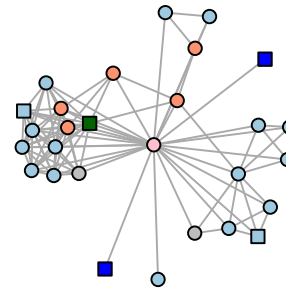
**MC02, 26 yrs Spain,
adequate screened**



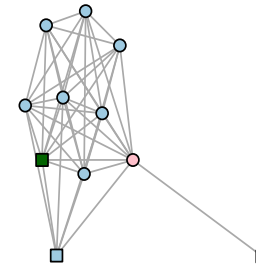
**MC03, 8 yrs Spain,
inadequate screened**



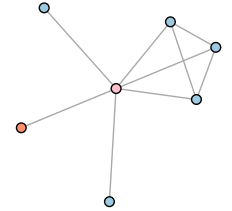
**MC04, 16 years Spain,
adequate screened**



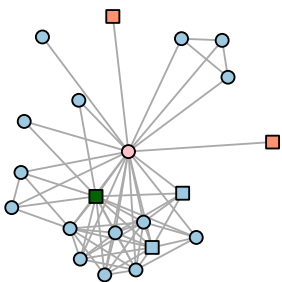
**MC05, 5 years Spain,
adequate screened**



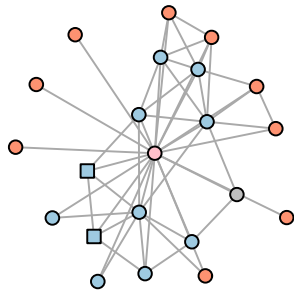
**MC06, 6 yrs Spain,
never screened**



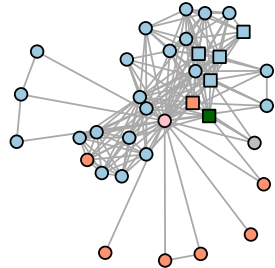
**MC07, 20 yrs Spain,
adequate screened**



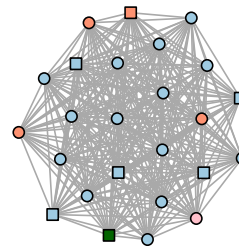
**MC08, 17 yrs Spain,
never screened**



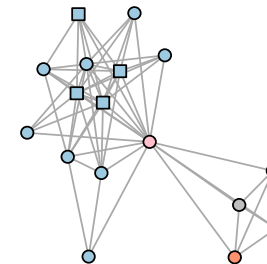
**MC09, 2 yrs Spain,
adequate screened**



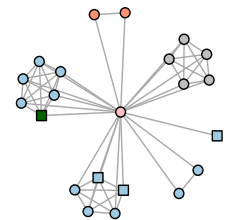
**MC10, 30 yrs Spain,
adequate screened**



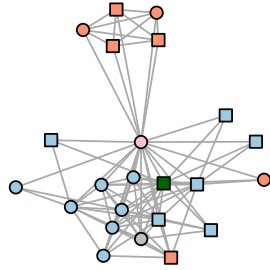
**MC11, 13 yrs Spain,
never screened**



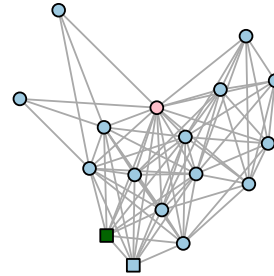
**MC12, 13 yrs Spain,
adequate screened**



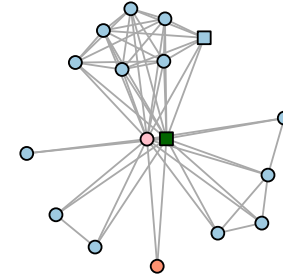
**PC01, 15 yrs Spain,
inadequate screened**



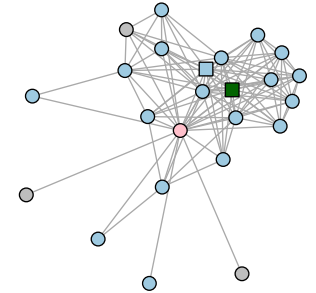
**PC02, 1 yr Spain,
adequate screened**



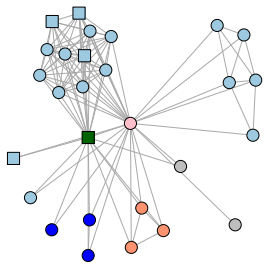
**PC03, 21 years Spain,
inadequate screened**



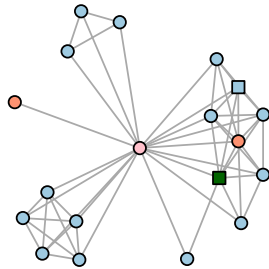
**PC04, 12 yrs Spain,
inadequate screened**



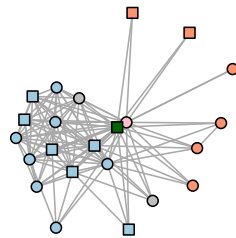
**PC05, 7 yrs Spain,
inadequate screened**



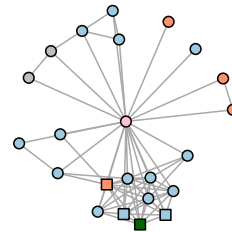
**PC06, 4 yrs Spain,
adequate screened**



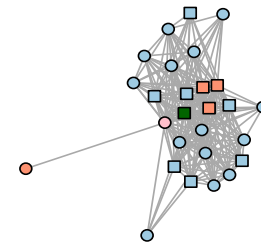
**PC07, 7 yrs Spain,
inadequate screened**



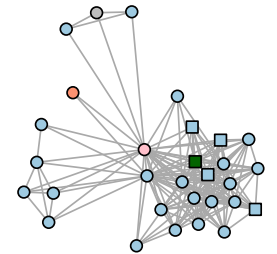
**PC08, 10 yrs Spain,
adequate screened**



**PC11, 10 yrs Spain,
never screened**



**PC12, 9 yrs Spain,
inadequate screened**



Appendix 9 Socio-demographic questionnaire.

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

Date/Time Interview place:

Participant ID:

1. **What is your birth date?** (DD/MM/YYYY) __/__/____
2. **What year did you migrate to Spain?**
.....
3. **How many people do you live with?**
I live alone
1
2
3
4
5 or more
Prefer not to answer
4. **Which language(s) do you speak most often at home?** (*You can tick more than one*)
Spanish
Catalan
Arabic-Darija
Urdu
English
French
Other (specify) _____
Prefer not to answer
5. **What is your marital status?**
Single
Married / Living with my partner
Separated
Divorced
Widowed
Other (specify) _____
Prefer not to answer
6. **¿Do you have children?** (If not, continue with question 8 ➡)
Yes

No

Prefer not to answer

7. How many children do you have?

1

2

3

4

5 or more

Prefer not to answer

 **8. Tick the box(es) in relation to your education (*You can tick more than one*)**

No academic school

Primary school

Secondary school

Vocational training

College – University degree

Koranic school

Other (specify) _____

Prefer not to answer

9. Are you employed?

Yes, I am employed (full-time, part-time, freelance)

No, I am unemployed (housewife)

Informal employment (without contract)

Retired

Prefer not to answer

10. Can you give an estimate of your annual household income?

Less than €12,000

€12,001 – €20,000

€20,001 – 30,000

€30,001 – 40,000

More than €40,001

I don't know

Prefer not to answer

11. Do you have public health insurance in Catalonia?

Yes

No

Prefer not to answer

12. How well can you communicate at the health centre or hospital without the assistance of translators?

- I always need a translator/mediator
- Most of the times I need a translator/mediator
- Sometimes I need a translator/mediator
- I do not need a translator/mediator
- Prefer not to answer

13. How often do you need someone to help you when you read instructions, pamphlets, or other written material from your doctor of pharmacy?

- Never
- Rarely / Sometimes
- Often
- Always
- Prefer not to answer

14. Do you know how to arrange an appointment with a gynaecologist in the public health system in Barcelona?

- Yes No Prefer not to answer

15. If you have had an appointment with a gynaecologist, have you ever taken a cytology (Pap smear)?

- Yes No I don't know Prefer not to answer

16. If you have taken a cytology (Pap smear), how long is it since the last time that you did so?

- Less than 1 year
- Between 1 and 2 years
- Between 2 and 4 years
- Between 3 and 5 years
- More than 5 years
- I don't know
- Prefer no to answer

17. HPV self-sampling is a new method that allows women to do the cytology or get a vaginal sample themselves at home. If you were offered the chance to use the HPV self-sampling, would you take up the offer?

- Yes No I don't know Prefer not to answer

18. How confident would you feel using HPV self-sampling?

- I would worry that I had not done the test properly
- I would feel very confident with adequate instructions
- I don't know
- Prefer not to answer

19. Would you say you are a religious person?

Very religious

Somehow religious

Very little religious

No religious at all

Prefer not to answer

20. Do you identify yourself as a Muslim person?

Yes

No

Prefer not to answer

Appendix 10 HPV self-sampling acceptability questionnaires.

HPV SELF-SAMPLING ACCEPTABILITY QUESTIONNAIRE

The following questions are to learn about your experience related to using the self-sampling device at home. We would appreciate it if you could answer all the questions below.

PARTICIPANT ID: _____

1. Self-sampling performed on (dd/mm/yyyy): ____ / ____ / _____

2. How was the experience of collecting the vaginal sample using a self-sampling device?

- Very good
- Good
- Neither good nor bad
- Bad
- Very bad
- Other: _____
- I don't know/I prefer not to answer

3. Was it easy for you to understand the self-sampling instructions?

- Yes, they were very clear and easy to understand
- Quite clear and easy to understand
- Normal, neither so simple nor so complicated
- It was a bit difficult for me to understand
- It was very difficult for me to understand the instructions
- Other: _____
- I don't know/I prefer not to answer

4. What do you think about the use of the self-sampling device?

- I found it very easy and simple to use
- I found it easy to use
- Normal, neither difficult nor very easy
- I found it a bit complicated to use
- I found it very difficult to use
- Other: _____
- Don't know / prefer not to answer

5. Is the self-sampling device easy to introduce in the vagina?

- Yes, it enters very easily without any problem
- Yes, although it takes a bit of work
- Normal / indifferent
- It took me a while to enter
- It was quite difficult for me to introduce it.
- Other: _____
- I don't know / I prefer not to answer

6. Do you think the sample has been collected properly?

- Yes, I'm sure



- Yes, although with certain doubts
- I'm not sure I picked it up right
- I'm sure I picked it up wrong
- Other: _____
- I don't know / I prefer not to answer

7. Did you feel any pain while collecting the self-sampling?

- No, I haven't felt any pain
- No, but I felt some discomfort
- Yes, although not very intense
- Yes, an intense pain
- Other: _____
- I don't know / I prefer not to answer

8. What other feelings have you experienced when collecting the self-sample?

Mark the intensity of each feeling with an X, being 0-none and 10-a lot, or mark " I don't know " if you are not sure / know the answer.

	<i>None</i>										<i>A lot</i>	<i>I don't know</i>	
	0	1	2	3	4	5	6	7	8	9	10		
<i>Comfort</i>													
<i>Calmness</i>													
<i>Normality</i>													
<i>Safety</i>													
<i>Privacy</i>													
<i>Shame</i>													
<i>Fear</i>													
<i>Anxiety</i>													
<i>Frustration</i>													
<i>Nervousness</i>													
<i>Others: _____</i>													

9. How long did it take you to collect the self-sample?

- Less than 5 minutes
- Between 6 and 10 minutes
- Between 11 and 15 minutes
- More than 15 minutes

10. Did you need any help to collect the self-sample or to understand the instructions?

- Yes, but only to understand the instructions
- Yes, to understand the instructions and for sample collection
- No, I've done it all by myself
- Other: _____
- I don't know / I prefer not to answer

11. Do you think the self-sample is safe?

- Yes
- No
- Other: _____
- I don't know / I prefer not to answer

12. Do you think self-sampling will cause you any harm in the future?

- Yes
- No
- Other: _____
- I don't know / I prefer not to answer

13. Would you trust the result of this test performed by yourself instead of by a healthcare provider?

- Yes
- No *Why?* _____
- Other: _____
- I don't know / I prefer not to answer

14. What would you prefer, self-sampling (collecting the sample yourself) or having the sample collected by the healthcare professional?

- Myself
- The healthcare professional
- Both options are fine to me.
- None of them
- Other: _____
- I don't know / I prefer not to answer

15. If the self-sampling device will be used in the future, order from highest (1) to lowest (6) preference where would you like to pick up the self-sampling device? (1 = option you like the most, 6 = option you like the least)

- In a healthcare centre (primary healthcare centre, gynecology centre (ASSIR), referral hospital)
- In a pharmacy
- In a post office
- Have it sent/delivered to my home
- In a community facility *¿Which one?*

- Other: _____
- I don't know / I prefer not to answer

16. Order from highest (1) to lowest (5) preference where would you like to return the self-sampling device? (1 = option you like the most, 5 = option you like the least)

- In a healthcare centre (primary healthcare centre, gynecology centre (ASSIR), referral hospital)
- In a pharmacy
- In a post office or mail box
- In a community facility *¿Which one?*

- Other: _____
- I don't know / I prefer not to answer

17. Would you like self-sampling to be used as a screening test for early detection of cervical cancer in the future?

- Yes
- No
- Other: _____
- I don't know / I prefer not to answer

18. Would you use the self-sample again as a screening test to detect cervical cancer early in the future?

- Yes Other: _____
 No I don't know / I prefer not to answer

19. Would you recommend using self-sampling for cervical cancer screening to a family member/friend?

- Yes
 No
 Other: _____
 I don't know / I prefer not to answer

If you have any other comments you want to share, you can write them below:

HPV SELF-SAMPLING NON-ACCEPTABILITY QUESTIONNAIRE

This questionnaire is to be completed by all women who participated in the study, but declined the invitation to try one or the two HPV self-sampling devices at home, or despite accepting the invitation and taking the devices home, they did not return the acceptability questionnaire within the expected timeframe (two weeks since they took the devices)

Those women who accepted the invitation to try the self-sampling devices, but did not return the acceptability questionnaire in two weeks, will be called by phone as a reminder and if they still want to participate in the trial, two more weeks will be given to return the acceptability questionnaire.

PARTICIPANT ID: _____

1. Date (dd/mm/yyyy): _____ / _____ / _____

2. Could you tell me the reason why you do not wish to participate in this trial?

- I have not time
- I am not interested in the study
- I prefer to go to a health centre or hospital and the sample to be taken by a doctor
- I am afraid of taking the sample by myself
- When I saw the device, it made me feel scared
- When I read the instructions, I found it difficult and I left it
- I think I will not be able to collect by myself the sample properly
- I found the device very big and I did not try it
- I prefer not to answer
- Other reasons _____

If you have any other comment that you wish to share, please, write it down here:

Thank you very much for your contribution!

Appendix 11 Illustrative excerpt from FGD and SSI qualitative analysis.

Selected quotations and themes		
Quotations	Themes	Topic
<p><i>“It’s the first time I hear about it. I’ve heard about HIV but not HPV” PC12</i></p> <p><i>“The only thing I know is that this disease can be transmitted due to lack of hygiene and through fungus, germs or through multiple sexual relationships with different people (...) The only cure is through hysterectomy, because I think it’s very difficult to cure, so that the only way, removing the uterus completely” MC12</i></p> <p><i>“They just told me that it’s a women’s health control to check that everything is ok” MC04</i></p> <p><i>“I thought they were going to check my vagina and when they introduced the stick inside, I thought they were taking a sample to check about my baby, that’s it” PC02</i></p> <p><i>“No, no. They only do this test when the woman is pregnant. If the woman is not pregnant, they don’t do this test, unless she has a history of cancer in her family (...) I did it and when I went to the doctor the next time, I asked for the test, and they told me that it’s not necessary” PC05</i></p> <p><i>“In theory we all have to stay virgin before marriage, but I know about men who live here (in Spain) and they are not married and live with Latin women and then they go to my country (Pakistan) to get married” PC05</i></p> <p><i>“You know, there are always people who are Muslim but they don’t care about these things [not to have extramarital sexual relations], but in principle Muslim people have lower risk to catch up this virus [HPV]” MC09</i></p>	<p>Poor knowledge about the disease</p> <p>Poor knowledge about the disease</p> <p>Inadequate information about the screening test – patient</p> <p>Inadequate information about the screening test – Language barrier patient</p> <p>Inadequate information about the screening test - patient</p> <p>Risk perception</p> <p>Risk perception</p>	<p>1. Knowledge and perceptions about cervical-cancer and screening</p>
<p><i>Either with the doctor or at home is ok, but I think at home you feel more comfortable and you don’t need to show your body, it’s better” PG03</i></p>	<p>Overcoming barriers related to</p>	<p>2. Women’s motivators to accept and use</p>

<p><i>“Some people feel shyness in front of doctors so that’s the advantage of doing it at home” PG308</i></p> <p><i>“I prefer to do it at home, you are more comfortable, you can do it without feeling embarrassed, you are not lazy and you can save time. It’s something we can do it, it’s not difficult” MG303</i></p> <p><i>“It’s much better to do it (self-sampling) at home, you don’t need an appointment with the doctor ... This kit is the solution for all the problems! I don’t have to explain so many times at the reception of the CAP (primary health centre) the reasons for the appointment with the gynaecologist... Because you need to have symptoms, otherwise, they will not check you up, you know? This is perfect, even if I need to buy it, it’s alright, I will pay and everyone would pay” PC05,</i></p> <p><i>“I prefer to do it myself at home and then return it to the pharmacy; you can avoid having to arrange an appointment and all the hustle” MC05</i></p>	<p>shyness and cultural values</p> <p>Overcoming barriers related to shyness and cultural values</p> <p>Convenient and comfortable</p> <p>Overcoming barriers related to access health services</p> <p>Overcoming barriers related to access health services</p>	<p>HPV self-sampling</p>
<p><i>“Personally, I would be afraid, I won’t dare to do it, I won’t know how to do it, I prefer to go to the doctor” MG305</i></p> <p><i>“What if I don’t get the sample correctly and I keep myself with the doubt? That’s why I say that I’ll be sure that the sample has been collected correctly with the doctor” MG002</i></p> <p><i>“People like me who don’t trust themselves in things like this (self-testing) will feel insecure of not doing it correctly and harm themselves or feel pain” PC06</i></p> <p><i>“I prefer to go to the gynaecologist because I will be 100% sure that the test is done correctly and the result is right” PC01</i></p>	<p>Lack of confidence to perform the test correctly</p> <p>Lack of confidence to perform the test correctly / Distrust the test result</p> <p>Lack of confidence to perform the test correctly / Fear to harm themselves</p> <p>Distrust in the test result</p>	<p>3. Women’s challenges to accept and use HPV self-sampling</p>

Appendix 12 Study information sheet and informed consent form in English.

The study information sheet and the informed consent form were available in four languages: Arabic, Urdu, English and Spanish.

BARRIERS AND FACILITATORS TO CERVICAL CANCER SCREENING AND ACCEPTABILITY OF HPV SELF-SAMPLING AMONG IMMIGRANT WOMEN IN CATALONIA, SPAIN

PARTICIPANT INFORMATION SHEET (SSIs)

Introduction

We would like to invite you to take part in our research study. Before you decide, it is important to understand why the research is being done and what it involves. We are happy to go through this information with you and answer any questions you might have. You can take your time to decide whether to take part. This study involves gathering information about women's health issues among women who were born in Morocco/Pakistan but now live in Catalonia, Spain.

What is the purpose of the study?

We aim to understand why women who were born in Morocco/Pakistan may not attend cervical cancer screening and whether they would be interested in using a self-sampling device at home. We are also interested in where women who were born in Morocco/Pakistan obtain health information and advice, and how these influence participation in cervical cancer screening.

Why have I been invited? Do I have to take part?

You have been invited to take part in this study because you were born in Morocco/Pakistan, you live in Catalonia, Spain, for at least one year and you are aged 30 – 65 years old. You can decide either to take part or not in the research. If you decide to take part in the study, you are of course free to withdraw at any time. You will not need to give a reason. Please, if you need more information or share any concern, contact us using the details at the end of this leaflet. Feel free to phone or email us. We will also be happy to meet you in person.

What will happen if I decide to take part? What will I have to do?

If you decide to take part in the study, we will ask you to sign a written agreement (or informed consent) prior to the interview. You will be asked to attend an interview which will last around 2 hours and will take place in a convenient place proposed by you. This interview will be split into two parts. The first part will be a social network mapping exercise; we will map together your social network of relatives, friends, workmates, etc. and we will gather some information about them and your conversations with them about health. The second part will be an interview. With your permission, the interview will be recorded, and the interviewer will take notes. The recording will be transcribed and translated into Spanish or English, if necessary. All notes will be anonymised to protect your identity and those of your social network members. We will also be interested in your opinion about the self-sampling material. After the session, you will be invited to take a kit of materials to collect the sample at home, consisting of two self-sampling devices, instructions and an information leaflet. You are free to decide not to use the material, although we would be interested in your opinion whether you decide to use it or not. To get your opinion, we will give you a

questionnaire to complete. If you decide to explore and use the self-sampling device, the collected sample will not be processed in the laboratory, so the sample result will not be available. However, we recommend that you get screened for cervical cancer at your health centre. In the case of needing more information or any other type of assistance, the community health agents and the intercultural mediators will support you and refer you to the corresponding services. You will receive a transport compensation for the time given to the research.

What are the possible risks and disadvantages of taking part?

There are not risks derived from this study. You may find it difficult to talk about some relationships and topics, for example, family or friends' cancer experiences. You are free to talk as much as you wish about your relationships with your family, friends, etc and any of the points discussed during the individual interview. All information you provide will be confidential.

What are the possible benefits of taking part?

The information we get from the study will help our knowledge and understanding of the barriers to cervical cancer screening within your communities and, ultimately, contribute to help increase Moroccan/Pakistani women's participation in cervical cancer screening programmes.

How will we use information collected about you? How confidentiality will be kept?

We will keep all information about you safe and secure. In compliance with Organic Law 3/2018 of December 5 and Regulation (EU) 2016/679 of the European Parliament and of the Council, of April 27, 2016, regarding the protection of physical persons in relation to the treatment of personal data and the free circulation of these data ("General Data Protection Regulation" or "RGPD"), in full application since May 25, 2018, as well as any other regulations based on these laws (UK RGPD). The data obtained and the information provided by you in this study is confidential and for the exclusive use of this study. Personal data will be processed according to RGPD. It is expected to keep the study data for a maximum period of five years. In addition to the rights contemplated by the previous legislation (access, modification, opposition and cancellation of data) you can also limit the processing of data that is incorrect, request a copy or transfer to a third party (portability) the data that you has provided for the study. To exercise these rights, or if you wish to know more about confidentiality, you should contact the main researchers of the study (see the contact persons section) or contact the data protection delegates (lop@iconcologia.net; dpo@lshtm.ac.uk). However, you have the right to contact the Catalan Data Protection Authority (dpd@ticsalutsocial.cat) if you are not satisfied. The information obtained will be codified (your name and address will be removed, and your data will have a code instead).

The information containing your name and contact details will only be available to the facilitators and researchers involved in the study. All data will be stored in an encrypted form on secure servers and will be accessible only to the research team. Data will be kept for a maximum of five years. Interviews notes will be anonymised. Names of people and places will be removed. Any other information that could identify you will be encoded.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason; all data gathered about you will be deleted if you wish so. We will not tell anyone about your decision to withdraw unless you want us to do so.

What will happen to the results of this study?

The study results, including direct quotes of your views, personal experiences and opinions shared during the interview, and social network maps will be published in an academic journal, as well as the funder website and other dissemination materials, such as policy briefs and conference abstracts. Your personal information will not be included in any of these publications and there is no way that you can be identified from it.

Who is organising and funding this study? Who has reviewed this study?

This study is funded by the Economic and Social Research Council, in the United Kingdom. It is coordinated by Catalan Institute of Oncology (ICO), London School of Hygiene & Tropical Medicine (LSHTM) and the Public and Community Health team of the International Health Unit of Drassanes – Vall d’Hebron, in Barcelona. The investigators have full responsibility for the project including monitoring the study process, looking after your information, and using it properly. All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and approved by the Research Ethics Committee of the collaborating centres.

Further information and contact details

Thank you for taking time to read this information sheet. If you would like any further information, please contact the below researchers who can answer any questions you may have about the study.

- Jone G. Lurgain - jone.g.lurgain@lshtm.ac.uk | 647 937691
- Paula Peremiquel-Trillas, paula.peremiquel@iconcologia.net | 932 607 337
- Hakima Ouaarab Essadek, hakima.ouaarab@vallhebron.cat |



**BARRIERS AND FACILITATORS TO CERVICAL CANCER SCREENING AND
ACCEPTABILITY OF HPV SELF-SAMPLING AMONG IMMIGRANT WOMEN IN
CATALONIA, SPAIN.**

INFORMED CONSENT FORM

Name of PI/Researcher responsible for project:

Statement	Please initial each box
I confirm that I have read and understood the information sheet for the above named study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
I understand that my consent is voluntary and that I am free to withdraw this consent at any time without giving any reason and without my medical care or legal rights being affected.	
I understand that data collected during the study may be looked at by authorised investigators, where it is relevant. I give permission for these individuals to have access to these records.	
I understand that data about/from me, including direct quotes, may be shared via a public data repository or by sharing directly with other researchers, and that I will not be identifiable from this information.	
I accept to be voice recorded during my study participation.	
I agree to me taking part in the above named study.	

Printed name of participant	Signature of participant	Date

Printed name of person obtaining consent	Signature of person obtaining consent	Date

A copy of this informed consent document has been provided to the participant.

Participant Identification Number:

Appendix 13 Confidentiality agreement form in English.

The confidentiality agreement was available in four languages: Arabic, Urdu, English and Spanish.

BARRIERS AND FACILITATORS TO CERVICAL CANCER SCREENING AND
ACCEPTABILITY OF HPV SELF-SAMPLING AMONG IMMIGRANT WOMEN
IN CATALONIA, SPAIN

CONFIDENTIALITY AND NON-DISCLOSURE OF INFORMATION AGREEMENT

Mrs. _____
Name, surname and ID

I agree not to share with third parties any information, comments, opinions or experiences expressed by the participants in the focus group discussions or interviews.

The information provided by the participants is confidential, in compliance with Organic Law 3/2018 of 5 December and Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons in relation to the processing of personal data and the free movement of such data (General Data Protection Regulation or “RGPD”), fully applicable from 25 May 2018, as well as any other regulations based on these laws (UK RGPD), and its use will be exclusive to this study.

Printed name	Signature	Date
--------------	-----------	------

Printed name of the investigator	Investigator signature	Date
----------------------------------	------------------------	------

A copy of this agreement document has been provided to the participant.

Participant Identification Number: _____

Appendix 14 Ethic Committees' approval letters.

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LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



Observational / Interventions Research Ethics Committee

Ms Jone Garcia Lurgain
LSHTM

12 July 2022

Dear Ms Jone Garcia Lurgain

Study Title: Barriers and facilitators to cervical cancer screening and acceptability of HPV self-sampling among immigrant women in Spain

LSHTM Ethics Ref: 26186

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Other	Research_Ethics_online_training_certificate_Jone G Lurgain	04/06/2021	
Other	GCP_PPeremiquel_2022	12/03/2022	
Investigator CV	CV_Jone Garcia Lurgain	29/04/2022	1.1
Investigator CV	CV_Paula Peremiquel	29/04/2022	1.1
Information Sheet	Information sheet_Jone Garcia Lurgain_29 April 2022	29/04/2022	1.1
Information Sheet	Informed Consent form_Jone Garcia Lurgain_29 April 2022	29/04/2022	1.1
Advertisements	Recruitment of participants add	29/04/2022	1.1
Protocol / Proposal	Research Protocol_Jone Garcia Lurgain_30 April 22	30/04/2022	1.1
Covering Letter	Cover Letter clarifications Jone G Lurgain_28.6.22	28/06/2022	1
Protocol / Proposal	Updated Study Protocol_Jone G Lurgain_28.6.22	28/06/2022	2
Information Sheet	Updated Participant Information Sheet_Jone G Lurgain_28.6.22	28/06/2022	2
Information Sheet	Updated Informed Consent Form_Jone G Lurgain_28.6.22	28/06/2022	2
Local Approval	Diet final PR140 22 010722	01/07/2022	1
Covering Letter	Cover Letter_4.7.2022	04/07/2022	2
Protocol / Proposal	Updated Study Protocol_Jone G Lurgain_4.7.2022	04/07/2022	2

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project

by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: <http://leo.lshtm.ac.uk>

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

Handwritten signatures of Professor David Leon and Professor Clare Gilbert. The signature on the left is 'David Leon' and the signature on the right is 'Clare Gilbert'.

Professor David Leon and Professor Clare Gilbert
Co-Chairs

ethics@lshtm.ac.uk
<http://www.lshtm.ac.uk/ethics/>

Improving health worldwide

**INFORME DEL COMITÉ DE ÉTICA DE LA INVESTIGACIÓN SOBRE
PROYECTOS DE INVESTIGACIÓN BIOMÉDICA**

El Comité de Ética de la Investigación, mediante el procedimiento rápido de evaluación de la documentación contemplado en sus Procedimientos Normalizados de Trabajo (esta aprobación constará en el Acta 15/22 de fecha 07/07/22), tras examinar toda la documentación presentada, sobre el proyecto de investigación con nuestra Ref. **PR140/22** titulado:

“BARRIERS AND FACILITATORS TO CERVICAL CANCER SCREENING AND ACCEPTABILITY OF HUMAN PAPILLOMAVIRUS SELF-SAMPLING AMONG IMMIGRANT WOMEN IN CATALONIA, SPAIN: A MIXED-METHOD STUDY”, código: **CALL Study (Cribratge for ALL)**

Documentos con versiones:

Protocolo	Version2 21st June 2022
Information sheet and informed consent form (FGDs)	Version 2 21st June 2022
Hoja de información al paciente y consentimiento informado (FGDs)	Version 2 21st June 2022
Information sheet and informed consent form (KIs)	Version 2 21st June 2022
Hoja de información al paciente y consentimiento informado (KIs)	Version 2 21st June 2022
Information Sheet and informed consent form (SSIs)	Version 2 21st June 2022
Hoja de información al paciente y consentimiento informado (SSIs)	Version 2 21st June 2022
Confidentiality and non-disclosure of information agreement	Version 2 21st June 2022
Acuerdo de confidencialidad y no divulgación de información	Version 2 21st June 2022

Presentado por la Dra. Paula Peremiquel Trillas, del Programa de Investigación en Epidemiología del Cáncer del Institut Català d'Oncologia de L'Hospitalet (ICO-L'Hospitalet), como promotora e investigadora principal, ha acordado emitir INFORME FAVORABLE al mencionado proyecto.

Que la composición actual del Comité de Ética de la Investigación es la siguiente:

Presidente	Dr. Francesc Esteve Urbano	Médico - Medicina Intensiva
Vicepresidenta	Dra. Pilar Hereu Boher	Médico - Farmacología Clínica
Secretario	Dr. Enric Sospedra Martínez	Farmacéutico - Farmacia Hospitalaria
Vocales:	Dr. Jordi Adamuz Tomás	Enfermero – Enfermería
	Sra. Anna Boix Traserra	Derecho - DPD
	Dra. Concepción Cañete Ramos	Médico - Neumología
	Dr. José Luis Ferreiro Gutiérrez	Médico - Cardiología
	Dra. Ana María Ferrer Artola	Farmacéutica - Miembro sanitario
	Dr. Xavier Fulladosa Oliveras	Médico - Nefrología
	Dra. Margarita García Martín	Médico - Oncología Médica
	Dr. Carles Lladó i Carbonell	Médico - Urología
	Dr. Josep Manel Llop Talaveron	Farmacéutico – Farmacia Hospitalaria
	Dra. Sara Larriba Bartolomé	Farmacia - Sanitario
	Sra. Sonia López Ortega	Graduado Social - Atención a la Ciudadanía
	Dr. Sergio Morchón Ramos	Médico - Medicina Preventiva
	Dr. Miguel Ángel Pavón Ribas	Biólogo- Miembro no sanitario
	Dr. Joan Josep Queralt Jiménez	Jurista
Dra. Gemma Rodríguez Palomar	Farmacéutica – Atención Primaria	
Dr. Petru Cristian Simon	Médico - Farmacología Clínica	

Que este Comité cumple la legislación española vigente para este tipo de proyectos, así como las normas ICH y las Normas de Buena Práctica Clínica.

Que en dicha reunión del Comité de Ética de la Investigación se cumplió el quórum preceptivo legalmente.

Lo que firmo en L'Hospitalet de Llobregat, a 1 de julio de 2022

SOSPEDRA
MARTINEZ
ENRIQUE -
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Dr. Enric Sospedra Martínez

INFORME DEL COMITÉ DE ÉTICA DE INVESTIGACIÓN CON MEDICAMENTOS Y COMISIÓN DE PROYECTOS DE INVESTIGACIÓN DEL HOSPITAL UNIVERSITARI VALL D'HEBRON

Sra. Mireia Navarro Sebastián, Secretaria del COMITÉ DE ÉTICA DE INVESTIGACIÓN CON MEDICAMENTOS del Hospital Universitari Vall d'Hebron,

CERTIFICA

Que el Comité de Ética de Investigación con Medicamentos del Hospital Universitario Vall d'Hebron, en el cual la Comisión de proyectos de investigación está integrada, se reunió en sesión ordinaria nº 544 el pasado 16/09/2022 y evaluó el proyecto de investigación **PR(AG)317/2022** promotor Institut Català d'Oncologia (ICO), titulado "*CALL Study - Barriers and facilitators to cervical cancer screening and acceptability of human papillomavirus self-sampling among immigrant women in Catalonia, Spain: a mixed-method study*" que tiene como investigador principal Sra. Ouaarab Essadek, Hakima del Servicio de Infecciosas de nuestro Centro.

Versión de documentos

Protocolo	versión 2 del 21.06.2022
HIP/CI - Paciente (FGDs)	versión 3 del 13.09.2022
HIP/CI - Participante (KIs)	versión 2 del 21.06.2022
HIP/CI - Participante (SSIs)	versión 2 del 21.06.2022
Solicitud de evaluación CEIm	versión con fecha 2022.07.28

El resultado de la evaluación fue el siguiente:

Aprobado

El Comité tanto en su composición como en los PNT cumple con las normas de BPC (CPMP/ICH/135/95) y con el Real Decreto 1090/2015, y su composición actual es la siguiente:

- **Presidente:**
IGNACIO FERREIRA GONZÁLEZ - Médico
- **Vicepresidente:**
VÍCTOR VARGAS BLASCO - Médico
- **Secretario:**
MIREIA NAVARRO SEBASTIAN - Química

Vocales:

- LLUIS ARMADANS GIL - Médico
- FERNANDO AZPIROZ VIDAUR - Médico
- VALENTINA BALASSO - Médico
- INES M DE TORRES RAMÍREZ - Médico
- ELADIO FERNÁNDEZ LIZ - Farmacéutico Atención Primaria
- INMACULADA FUENTES CAMPS - Médico Farmacólogo
- JAUME GUARDIA MASSÓ - Médico
- JUAN CARLOS HORTAL IBARRA - Profesor de Universidad
- MARIA LUJAN IAVECCHIA - Médico Farmacólogo
- ALEXIS RODRIGUEZ GALLEGO - Médico Farmacólogo
- JUDITH SANCHEZ RAYA - Médico
- PILAR SUÑÉ MARTÍN - Farmacéutica Hospital
- GLORIA GÁLVEZ HERNANDO - Personal de Enfermería
- ESPERANZA ZURIGUEL PEREZ - Personal de Enfermería
- ANA BELÉN ESTÉVEZ RODRÍGUEZ - Abogada experta en protección de datos
- ROSER COBOS BAQUÉS - Abogado
- SANTIAGO ESCRIVÀ DE ROMANÍ MUÑOZ - Médico
- ANTONIO MORENO GALDÓ - Médico

En dicha reunión del Comité de Ética de Investigación con Medicamentos se cumplió el quórum preceptivo legalmente.

En el caso de que se evalúe algún proyecto del que un miembro sea investigador/colaborador, éste se ausentará de la reunión durante la discusión del proyecto.

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Sra. Mireia Navarro

Secretaria técnica CEIM HUVH