

Preference-Sensitive Apomediative Decision Support Is Key to Facilitating Self-Produced Health

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Abstract. In the health capital model, the main function of health services is not to produce health, but to support the person in their self-production investments. In the health context there are three types of decision support tools, depending on the role of the provider (e.g. clinician) and person. *Non-mediative* tools are designed to help the clinician decide what is best for the patient. *Intermediative* Patient Decision Aids are designed to help the clinician and patient decide together, in an encounter, what is best for the patient. *Apomediative* Personalised Decision Support Tools are designed to help the person decide what is best for themselves, including whether to seek a professional consultation and/or to prepare for, and engage in, an intermediative consultation. Only preference-sensitive apomediative support tools ensure that the key requirements of self-produced health are met, along with legally informed and preference-based consent to any subsequent provider action. The desirable form of apomediative support is a publicly accessible, direct-to-citizen, provider-independent, multi-criteria analysis-based decision support of the sort available in many other areas of self-production. *Which* (UK), *Tænk* (Denmark), *Choice* (Australia) and numerous other comparison magazines and websites provide independent multi-criterial support for decisions on, for example, which food and transport to buy to self-produce nutrition and movement. A personalised decision support tool for the statin decision is provided as illustration: Should I go to my general practitioner and ask for a statin prescription or go to discuss taking statins, in the light of the preliminary opinion of the tool?

Keywords. apomediative, inter-mediative, self-produced health, health capital, decision support tool, multi-criteria decision analysis

1. Background: the Health Capital paradigm

In the health capital paradigm [1–5], an individual person has, at any point of time, a stock of health capital. It is valued in terms of its future returns, both as a source of utility in itself and its yields in areas of life beyond health (work, leisure, etc.) for the person and their significant others. The person's initial stock of health capital is inherited at conception. Their health asset stock depreciates through life as a result of biological aging, but, if in any period during life, the amount of health-enhancing investment exceeds the amount of health-depletion by more than the amount of depreciation, the

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stock of health capital will have grown. If vice versa, the stock will have fallen. *To the extent they are in control* of their actions and have the relevant resources, including financial ones, to implement their choices – an extent which varies from place to place and individual to individual - the person's health capital is *self-produced*. In this *production* role they spend time, effort, and money acquiring inputs that enhance or deplete their health through *consumption* of goods and services.

Among these consumed inputs are *health and medical goods and services*. The person's demand for health services is therefore derived from their demand for health. In the health capital paradigm, the function of health services (as of food and transport services) is not to produce health, but to support the person in their self-production of health (as of meals and movement). Health professionals, such as GPs, can provide decision support to the individual in deciding how to enhance their health stock, or adapt to its depreciation. In many situations, such as hospitals, they can also supply the goods and services (tests and treatments) necessary to implement the decisions, in the same way as the supermarket supplies the food necessary to implement meal decisions, and the transport system supplies the vehicles necessary to implement movement decisions.

Given the challenging task of obtaining and integrating personalised information and preferences, decision support is essential for the informed and preference-based decision making that is key to optimising self-produced health.

2. Types of Decision Support Tool for self-produced health

In the health context we can distinguish main three types of Decision Support Tool (DST), depending on the role of the provider (here, clinician) and person [6].

Non-mediative Clinician Decision Support Tools (often misleadingly called Clinical Decision Support Tools) are designed to *help the clinician decide what is best for the patient*. Clinician's resistance to even such *non-mediative* DSTs has been documented by Liberati et al., along with the nature and sources of the resistance [7].

Intermediative Decision Support Tools (often called Shared Decision Making Support Tools or Patient Decision Aids) are designed to *help the clinician and patient decide together what is best for the patient*. The options included in the aid are often restricted or 'censored' to those which the clinician feels relevant to the patient. The attempts by Elwyn and others to introduce *intermediative* decision aids into practice, such as Option Grids or Mayo Cards, have also failed to overcome the resistance of many clinicians, extending to not using the aid despite having agreed to do so, or not delivering it in the intended way [8-11].

Apomediative Decision Support Tools are a 'direct-to-citizen' resource designed to *help the person decide what is best for themselves*, including whether to seek a health service consultation and/or to prepare for, and engage in, an intermediative consultation. Insofar as they contain an uncensored set of options and commit to the personalised assessment of benefits and harms of all these, apomediative support tools help ensure that the key requirements of self-produced health are met, along with legally informed and preference-based consent to any subsequent provider action. The clinician will often become involved in the making of the supported decision subsequently – intermediatively - not only because they have greater relevant knowledge (e.g. ability to identify contraindications), but also because only they have the power to order a test, prescribe a medication, or refer for, or undertake, surgery.

The person can agree to a switch of a previously-completed apomediative DST into

a clinician-managed intermediative tool, but this does not change its fundamental nature and intention, which is totally different from that of a pure intermediative one [6].

Full implementation of the person-centred paradigm, as captured in the Digital Health Manifesto [12], requires ‘dually-personalised’ decision support tools. In these the person’s personal preferences (criterion weightings) are combined with the most personalised estimates available for the performance of all options on the criteria important to the person. ‘Single personalisation’, involving only the latter, does not respect the preference-sensitivity of the decision.

3. Apomediative decision support for self-produced health

Apomediation can take multiple forms, including ‘Dr Google’, social media networks, patient groups and librarians, so the quality of apomediative support can vary enormously. In order to ensure its analytical and empirical credibility, one key criterion is independence from providers with their own conflicts of interest, whether financial, organisational or professional.

The desired form of apomediative support is of the sort available in other areas of self-production. *Which* (UK), *Tænk* (Denmark), *Choice* (Australia) and many other comparison magazines and websites provide classic examples of DSTs that support the decision as to which washing machine, which holiday package, or which bicycle to buy in carrying out self-produced home maintenance, self-produced leisure, and self-produced transportation. These DSTs could become more personalised by providing interactive weighting of the multiple criteria on which the products are rated, but the majority have pre-entered criteria weights, so as to be able to identify a ‘Best Buy’ or ‘Best Value’ for the whole readership. Personalised Decision Support Tools (PDSTs) also differ in having the person provide the *ratings* for those criteria where they are the expert, e.g. treatment burden and burden of out-of-pockets costs.

To permit analytically-credible, dually-personalised, home-based support at or near the point of decision, PDSTs should take the form of computerised, online implementations of Multi-Criteria Decision Analysis (MCDA), a technique which uses the accessible structure and ‘language’ of comparison websites.

The PDSTs in health must, like the above examples, be publicly accessible – not available only through a health professional or provider – even if they are not free.

In self-produced health such PDSTs will contribute significantly to the ability of the person to consent to actions (testing, treatment, etc.) following from a decision taken with a health provider – as well as help them decide whether to engage with a health provider in the first place. We argue that only final decision deliberation preceded by a formal MCDA-based PDST (at home or in the clinic) can meet the ethical requirements of person-centred care. Furthermore, the PDST embodies the transparency and explicitness necessary for the legally-required informed and preference-based consent to any subsequent action in which a health provider is involved.

Concerns about the ability of persons to engage with, and properly interpret the output from a PDST, must be addressed in the tool, but informed consent to engaging with it is required on opening. A disclaimer makes clear that apomediators do not have the ‘duty of care’ to persons that health professionals have to patients. On the other hand, they must respect all the rights of consumers to accurate and unbiased information and transparency in any processing of it.

The PDST produces an *opinion* not a recommendation – an opinion which is

normally *preliminary* to a ‘deliberative’ phase that ends with a decision. This phase may vary from a few seconds cogitation by the person by themselves (e.g. ‘I will go with the winning option’) to extensive consultations with other sources, including, in a switch to intermediation, with health professionals who may be able to draw on more sophisticated biomarkers. The decision taken at the end of the deliberation phase may or may not be in line with the preliminary opinion. Concordance, or lack of it, between the preliminary opinion and the final decision cannot be regarded as an indicator of its value.

4. Self-sourced inputs into apomediative decision support tools

It is in the nature of the more involving forms of apomediative decision support that many inputs are self-sourced. Tools developed in the MCDA technique usually require four broad types of self-sourcing. 1. Completion of an online instrument. 2. Obtaining output from a personal device, home kit, wearable and/or, where possible, the person’s electronic health record. 3. Rating how well all options perform on those criteria where the person is the expert. 4. Assigning relative importance weights to the criteria.

The illustration provided here is a dually-personalised decision support tool for the statin decision: Should I go to my general practitioner and ask for a statin prescription, or make an appointment to discuss statins in the light of the tool’s preliminary opinion?

The tool involves the person completing an online instrument to obtain estimates of their personalised risks of All-Cause Mortality and Cardio-vascular Mortality in the next ten years; self-assessing their blood pressure and total cholesterol level, which are the inputs required, along with age, sex and smoking status, to complete the EuroSCORE-based instrument; self-rating the treatment burden of statins; and assigning importance weights to four criteria (10 year mortalities, statin side effects and statin burden).

The tool is derived directly from the study of Støvring et al. 2013 [13] and simply translates the data in that study into decision support format and adds two of the criteria that are needed in a PDST. To engage with the tool, go to <https://goo.gl/H7P51r>.

Simpler forms of apomediative decision support tool require less involvement. In the modification of the statin selection aid of Naci et al. to make it preference-sensitive and yield personalised option scores (<https://goo.gl/oVPPab>) the person need only supply their criterion weights. In the translation of the MAGIC decision aid on aspirin as primary prevention to achieve the same objective (<https://goo.gl/5MdWFA>), the person supplies their criterion weights and ratings for the ‘practical consequences’.

5. Conclusion

To the extent that personalised health is self-produced health, high quality apomediative decision support tools are required. Such tools will be able to draw on the outputs of a rapidly increasing number and range of home tests, wearable devices, health records and internet resources. Online assessment and evaluative instruments should be developed and/or modified to facilitate the apomediative approach, as well as to develop health service providers’ competencies in using these tools in subsequent intermediation.

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