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Metro Mapping: development of an innovative methodology to co-design care paths to support shared decision making in oncology

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IG died on April 13th 2022

Shared decision making and service design

Treatment decision-making can be complex, notably when there are multiple treatments available, with different (probabilities of) benefits and harms, for example, survival and side effects.¹ It is precisely in these complex situations that the preferences of the patient are of utmost importance, as the trade-offs of benefits and harms are subjective and concern patients' lives.² In such trade-offs, shared decision making (SDM) has gained momentum as a strategy to include both the best available evidence and the patient's preferences.³

Healthcare professionals generally have positive attitudes towards SDM, but in practice SDM is still not often applied.^{4,5} Challenges for patients do not only relate to what happens during the decision-making encounter, but also to how healthcare is organised (eg, lack of time and of continuity of care, and untransparent care trajectories).⁶ Decision-making further often involves a sequence of occasions before, during and after the encounter, where each occasion is a 'chapter in the entire story of a person's illness'.⁷ This adds to the challenges patients face in preparing for decision-making occasions, especially if these are unplanned. Implementation of SDM therefore should also focus on the longitudinal nature of decisions, and on the relations between patients, their significant others, and their clinicians, to support patients in their confidence to participate in decision making.² For these reasons, a service design approach is appropriate to support SDM.

Service design is concerned with systematically applying design methodologies to the design of services.⁸ It deals with improving exchanges between service providers (in our case clinicians) and users (patients and their significant others).⁹ SDM can be considered a service, to be delivered throughout a patient's entire care trajectory, with all 'touch points' (encounters, leaflets, etc) as parts of a consistent system to support SDM. A cornerstone of service design is co-creation, consisting of co-design and co-production. In our case, providers and users actively participate in the (re) design of the care path, the co-design phase. After this, a clinician and an individual patient share the decision making about the individual's treatment

trajectory, the co-production. The design perspective on service allows for interventions that address both the organisation of care pathways and the experiences of patients in interactions with others in those pathways.

We developed the service design methodology 'Metro Mapping' to improve SDM in oncology, using pancreatic cancer as an example. In this paper, we describe the development of this methodology and the first evidence on its implementation.

How we developed Metro Mapping

Metro Mapping originated from the unfortunate co-occurrence of research aiming to improve SDM through service design and the diagnosis of pancreatic cancer of the husband of the researcher (IG). She wrote an autoethnography during the first 6 months of her husband's diagnostic and treatment trajectory, during which they both experienced difficulties to participate in decision making despite being highly educated and the wife doing research on SDM. These difficulties led her to carry out experience mapping in interviews with clinicians and other patients with pancreatic cancer, using design methodology such as visualisation and photo elicitation.⁷ The autoethnography and the interviews gave rise to four themes: (1) Decision making as a sequence of (un)planned moments before, during, after the encounter; (2) Work for patients and relatives to acquire/understand/recall information; (3) Often unclear roles and tasks; and (4) Unexpected energy drains or boosts that influence the empowerment to participate in SDM. The latter often were related to planning and logistics, the physical context (eg, wayfinding), or medical devices without clear instructions.⁷ These four interconnected themes were integrated in a new service-design framework to support SDM, Metro Mapping. It consists of five so-called layers relevant for service improvement (of which the need was revealed by the four themes). The layers involve principles and methods of service design, such as co-design (involving all stakeholders), and visualisation. **Figure 1** shows the resulting Metro Map, with colours indicating the phases of diagnosis and treatment (eg, blue is the diagnostic phase, green



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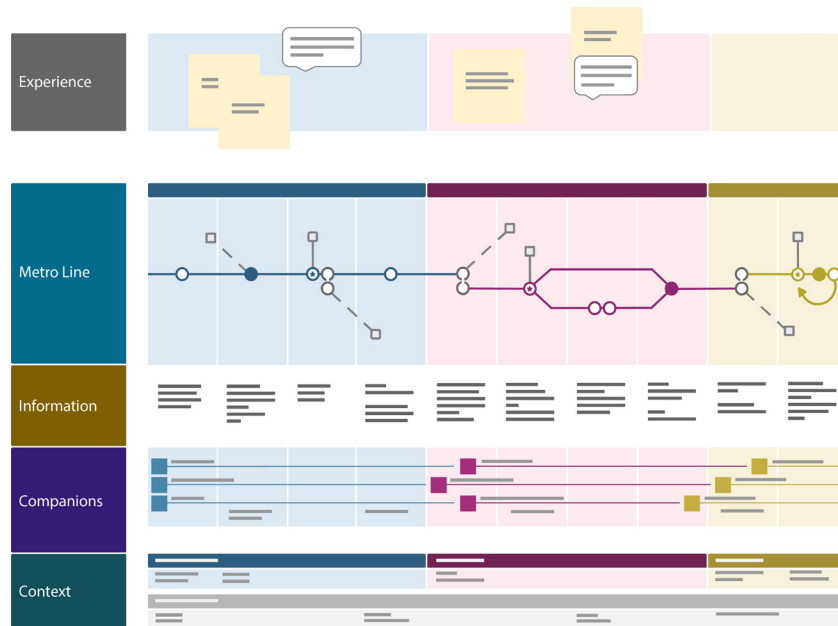


Figure 1 The Metro Map for an oncological treatment trajectory, showing the five layers of the Metro Mapping methodology.

surgery). Layers 3–5 are aligned to the phases of the treatment trajectory, as shown by the colours.

Layer 1. Experience. Using current experiences of patients, their significant others and clinicians, the existing trajectory is visualised, and difficulties encountered are mapped on it. The experiences are elicited in interviews or focus groups, or obtained from observations, and can be described using quotes, themes, and photos or illustrations.

Layer 2. Metro Line. Visualising the redesigned evidence-based treatment trajectory, including logistics (planning and organisation) and recognisable instances of decision making, with possible connections from one metro line to another (eg, from medical oncology to surgery). Each phase in the trajectory is indicated by a specific colour. The connecting stations are indicated with specific symbols, as are the decision moments. In this way it becomes clear what the choices are, on what these depend (eg, results of a scan, or preference of the patient), and during which moments a patient is in touch with a clinician (eg, for a blood test, or discussion of the result of a scan).

Layer 3. Information. Indicating what information needs to be provided to the patient about disease and treatment and when, at the right time to prepare for a decision, or to understand the treatment process. This layer also indicates in what way information can be obtained: in an encounter, from a website, app, video or otherwise. In this way patients can obtain the information in the manner that best fits them. By aligning the information layer with the metro line, it becomes clear that with a change in the trajectory new information may be needed.

Layer 4. Companions (figure 2). Charting all people involved in decision making and care, including both the patient's significant other and clinicians, and describing their roles, tasks and collaboration. Patients know what to expect from whom at what point in time. The companions ensure that the patient receives the care that fits the patient, and that he or she can cope with treatment. By charting the companions aligned with the metro line, it becomes clear to clinicians how to arrange and plan handovers, which patients often experience as stressful.

Layer 5. Context. Concerning the physical context in which the trajectory takes place, and the artefacts (physical objects) that patients may encounter. The physical context may be at home, or in, for example, a primary care practice or a hospital. One can think of consultation rooms, but even of parking garages. Which route do patients, their families and clinicians follow, and how are they influenced by what they see or experience? Artefacts may concern devices patients use, for example, a port-a-cath for the administration of chemotherapy.

The result of Metro Mapping, the co-design process of clinicians, hospital innovation managers, a service designer and patient representatives, is the Metro Map, a visualisation of possible trajectories, Metro Lines, and for each line an overview of the other layers. In addition, the opportunities for adaptation are mapped. To support the process, co-design tools have been produced for the layers Information and Companions. The Metro Map supports the clinician in the subsequent co-production, during SDM in the clinical encounter, of an individual trajectory. For this is the ultimate aim of Metro Mapping: to support individual patients and their clinicians in the process of SDM. Together they plan a route, the Metro Line, that fits the needs, goals and preferences of the individual patient. This route, with its accompanying information, is available to the patient (as a so-called Care Path Navigator, see metromapping.org/carepath-navigator for an example). It is flexible in case of changes to the circumstances and known to the patient to be so.

The implementation of Metro Mapping in three centres

Metro Mapping was tested in the re-design of the care path of locally advanced pancreatic cancer at the Erasmus Medical Centre Rotterdam. The first layer, Experience, had been the prelude to the development of the methodology,⁷ so was not repeated. For layers 2–5, co-design would ideally be carried out with clinicians and patients in the same session(s). Due to the vulnerable situation of the patients with pancreatic cancer—or their widowed partners—it was decided to perform interviews with them individually and hold the co-design sessions with clinicians and hospital



Figure 2 Co-design tool for the layer Companions, with an inner circle including the patient and his/her significant other at the centre and the other people involved on a regular basis, and an outer circle with people who may ad hoc be drawn in, for example, a dietitian, a psychologist.

innovation managers only. Since the researcher was partner of a patient with pancreatic cancer, she managed to build close relationships with the patients during preceding generative interviews,⁷ as was recommended by Hendriks *et al* for co-designing dementia care.¹⁰ She reflected about her insight knowledge with the healthcare professionals. In this way she was able to form the connection between patients and the clinical co-design team and could integrate insights from both stakeholder groups.

In Layer 2 a new metro line was co-designed and was visualised using Microsoft Visio building blocks (see metromapping.org/en). The procedure became an example for developing a Metro Map for patients with resectable pancreatic cancer at Radboud University Medical Centre. In this project, Empower2Decide, co-design involved general practitioners, gastroenterologists at six referring hospitals, and a pancreatic cancer team at the tertiary referral centre. With the Metro Map, the collaborators were able, for example, to indicate instances where SDM is relevant, and those where handovers to another specialty require attention. Finally, the methodology was used by the design researcher (IG) in the Deventer Hospital, when she herself was diagnosed with breast cancer.¹¹

For Layer 3 in Empower2Decide, information was gathered from the websites of the hospital, and of the pancreatic cancer clinician and patient organisations (the Dutch Pancreatic Cancer Group and Living with Hope, respectively).

In Layer 4 information for the patient is now available to clarify tasks and roles of healthcare professionals (and of themselves) in all three centres.

Layer 5 is still in an explorative phase. It addresses the importance of the physical context of patient experiences in the hospital and at home, in both pancreatic cancer settings, but also in the breast cancer care path in the Deventer Hospital.

Discussion

Metro Mapping is a methodology for co-designing care paths and the associated decision moments in a person-centred, holistic and iterative way, with active involvement of patients, clinicians and

hospital innovation managers. Its strong points are the flexibility for heterogeneous care paths and its intuitive visual language. The resulting Metro Map can be used in a process of SDM with an individual patient, to decide on the specific trajectory (the Metro Line) that best fits that individual. Metro Mapping strongly resonates with the current international focus on Value-Based Health-Care,^{12 13} which uses care path re-design to address coordination of care and increase patient-centredness, including SDM.¹⁴

The current focus of the method is oncology, but in the future the implementation of Metro Mapping in other fields is expected. In the Netherlands, the methodology has already been used in the COVID-19 care path at Radboud Medical Centre, in 14 care paths in the LUMC Value-Based HealthCare programme, and interest has been expressed by teams in transgender care and dementia care. In Europe, the further development and implementation of Metro Mapping will be studied in the '4D PICTURE' project, financed in the Horizon Europe programme (2022–2027).¹⁵ In this project we will implement Metro Mapping in Denmark and Spain in addition to the Netherlands, and we will enrich Metro Maps with data-driven decision support tools, such as prediction models and artificial intelligence tools.¹⁶ We will evaluate the effect of the method on both the decision-making process (eg, SDM) and outcomes (eg, treatment choice, regret), and assess experiences of patients, their significant others and clinicians. For some layers, more than others, reliable and high-quality evidence is available (eg, Information). The layers Companions and Context are new to both care path design and patient education and need more research. Generic interventions will be additionally developed and tested for use in practice. But the methodology, a manual, and co-design tools are already available ([Metromapping.org/en](http://metromapping.org/en)). With these we hope not only that patients and their significant others are empowered, but also that clinicians are supported in their attempts to share decisions with patients.

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Contributors AS was involved in planning and supervising the conducting of the work, wrote the manuscript, and is responsible for the overall content as guarantor. IG was involved in planning and conducting the work, and her earlier presentations provided the basis for the manuscript. JB was involved in developing the methodology and in the critical revision of the manuscript. MM was involved in planning and supervising the conducting of the work, and in the critical revision of the manuscript. JR was involved in conducting the work, and in the critical revision of the manuscript. MK was involved in the critical revision of the manuscript. MvdK was involved in conducting the work and in the critical revision of the manuscript. CvE was involved in conducting the work and in the critical revision of the manuscript. DS was involved in planning and supervising the conducting of the work, and in the critical revision of the manuscript.

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Competing interests AMS and JR are board members of the not-for-profit Metro Mapping Foundation (no honorarium involved). JB is managing director of Design Studio Panton Deventer, who provide consultation in the use of Metro Mapping. The other authors declare no conflict of interest.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants. The Medical Ethical Review Committee of the Erasmus Medical Center Rotterdam waived the necessity for medical ethical approval under Dutch law, as subjects were not subject to procedures nor were they required to follow rules of behaviour (protocol number MEC-2018-1403 for which approval was exempted). Participants gave informed consent to participate in the study before taking part.

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