

## SUPPLEMENT TO 'MAKING CARE FIT MANIFESTO': APPROACH

### Setting

The online 'Making care fit partnership' meeting took place on March 4<sup>th</sup> and March 11<sup>th</sup> 2021, using Zoom Cloud Meetings and Miro online collaborative whiteboard platform. This partnership meeting was supported by the Royal Netherlands Academy of Arts and Sciences (KNAW) and the Dutch Research Council (NWO) The Netherlands Organisation for Health Research and Development (ZonMw) (016.196.138).

### Participants

A heterogeneous, international and interdisciplinary group of patients, caregivers, clinicians, researchers, designers, and policy makers participated in the meeting. Participants were invited by the faculty, invited by other participants, or self-registered. They came from Denmark, England, France, Ireland, Scotland, the Netherlands, and the United States.

*Patients* had lived experience with ENT cancer, Type 1 Diabetes, or Genetic disorders.

*Caregivers* had a relation to a patient as a Mother, Daughter, or Partner.

*Clinicians* were General Practitioner, Public health physician, Nurse, Internist, Physician, Junior physician, Case manager, Pediatrician, Diabetologist, or Diabetologist for young adults.

*Researchers* with a focus on Organizational psychology, Vulnerable patients, Placebo/Nocebo effects, Uncertainty, Shared decision making, Patient-clinician communication, Value-based healthcare, Argumentation, Ethics, Sociology, Epidemiology, and/or Treatment burden.

*Designers* with a focus on Service design, Design methods, and/or Support tools.

*Policy makers* were Medical Director or Quality improvement specialist.

Our *collaborators* were an ENT surgeon, a Critical care clinical pharmacist, a Psychologist and a Psychiatrist.

### Procedure

Prior to each meeting, participants reflected on the concept and implementation of Making Care Fit using written reflection questions and short inspirational video interviews with the collaborators.

#### *Day 1: concept of Making Care Fit*

Participants introduced themselves with one PowerPoint slide, displaying a 50-word text on their background and interest, and two visuals representing 1) themselves, and 2) their vision of making care fit. Throughout the meeting, participants actively used the chat function to ask questions or engage in a parallel conversation.

The meeting started with an exercise to search for an object in their own house that would be relevant to their idea of Making Care Fit. Participants brought for example a DIY loop (that connects an insulin pump to their phone), a surgical saw (to represent (avoidance of) cutting), an artwork of an owl (to represent wisdom), a chess pawn (reminding us that patients are not abstract), and duplo (to build and rebuild).

Maria Kristiansen represented the Cared-for perspective in her keynote lecture ‘Fitting care to whom? Blurry patients and perceptive doctors’. Marleen Kunneman presented findings of exploratory research in the area of Making Care Fit in her keynote lecture ‘Making Care Fit: First steps in research’.

Participants then used the web-based collaboration tool Miro to co-create a vision of care with the caption: ‘It is 2031 and thanks to the international Making Care Fit program, everything changed! Make up an anecdote of something happening in 2031 that illustrates how healthcare has changed for good’. A selection of anecdotes can be found in **Table 1**.

**Table 1.** Selection of anecdotes from 2031, when healthcare changed and care fits.

1. I just switched from the pediatric clinic to the young adults clinic. I have access to resources that help me to transition from high school to university, so I don't feel alone in my care.
2. There's so little noise when I talk to my clinician.
3. I am not limited by time in consultations with my patients and can truly figure out what my patients need and provide this or refer properly.
4. The culture at my workplace at the hospital truly acknowledges the patient as co-partner in care and believes we should make care fit.
5. My grandfather who turned 99 this year could get his yearly COVID vaccine at the local health center instead of having to travel 45 minutes by car.
6. A doctor takes time to write condolence cards.

Finally, participants worked in five small groups on Miro to elaborate on a preliminary description of Making Care Fit and identify challenges calling for more research. The description was: ‘Care plans should fit patients and their lives, that is, care should be responsive to the patient's problems, maximally supportive of patient priorities, while minimally disrupting patients' lives and loves’. The groups focused on the following issues:

- What being ‘responsive to patient's problems’ to us really means, is... [1]
- and ‘maximally supportive of patient priorities’ even goes so far as... [2]
- We know minimally disrupting patients' lives is a big challenge, because if you take that seriously, it even includes... [3]
- And we believe we would make a big difference in minimally disrupting patients' loves by... [4]
- The above description of ‘care that fits’ is not complete/correct, because it does not pay attention to... [5].

After the meeting, the faculty analyzed the responses from the participants and identified the following themes relevant to Making Care Fit: 1) Understand patient preferences, 2) Enable patients to make care fit, 3) Navigate tensions for clinicians, 4) Support patient-clinician collaboration, 5) Make care fit at organizational level, and 6) Relevant outcomes and evaluations of efforts. The faculty also drafted a Manifesto.

*Day 2. Manifesto and future priorities*

Victor Montori represented the clinician's perspective in his keynote lecture 'Making care fit to build health in people with chronic conditions'.

Next, participants edited the draft Manifesto on Miro and all suggestions were discussed in plenary. We then opened a breakout room for each previously identified theme relevant to Making Care Fit. Participants each chose one or several breakout rooms to formulate relevant research questions and future priorities to forward the field of Making Care Fit, both in research and clinical practice. Subsequently, we asked participants to read through and provide thoughts and suggestions to research questions in all themes. We discussed all input in plenary, before asking participants to assign a total of five votes to the issues to be prioritized. The outcomes of this vote are presented in **Table 2**.

**Table 2.** Research questions and future issues to be prioritized

Theme	Research question	Votes (N)
5) Make care fit at organizational level	How does 'Making Care Fit' fit into existing healthcare delivery systems? How can we apply principles of 'Making Care Fit' at organizational levels?	9
6) Relevant outcomes and evaluation of effects	What does good care do? How does what care does at a micro level relate to what care does at a macro level?	9
4) Support patient-clinician collaboration	What are the key building blocks to establish a well-functioning relationship over time? How can we develop a well-functioning relationship when there is an unknown time frame to build the relationship?	7
2) Enable patients to make care fit	How can we tailor the information, tools, guidance etc. to the different healthcare settings, individual health needs and capabilities of the patient? Being responsive to differences between acute and chronic care needs.	6
4) Support patient-clinician collaboration	How can we help clinicians to get a good impression of what it is like to be that patient ('walk in their shoes' for a while) using e.g. patient empowerment tools and electronic records?	6
3) Navigate tensions for clinicians	What obstacles are clinicians experiencing related to the patient relationship/making care more personally right for patients? What about obstacles that cannot be readily changed? How could we work around such obstacles?	5

Finally, participants completed a writing exercise. We asked them 'What are you taking with you for tomorrow and the coming year?'. They were asked to 'word dump', i.e., to write/type for two minutes, continuously moving their pen/fingers and not thinking about sentence structures or coherence.

*Post-meetings*

After the meetings, the authors worked together to draft a 'Making Care Fit Manifesto'. In several rounds, drafts were circulated for feedback from the working group, until the working group reached consensus on the content and the wording of the Manifesto.