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Making care fit manifesto

Marleen Kunneman ,[1,2] Ingeborg P M Griffioen,[1,3] Nanon H M Labrie,[4] Maria Kristiansen,[5] Victor M Montori,[2] Mara M van Beusekom,[6] the Making Care Fit Working Group

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For numbered affiliations see end of article.

Correspondence to:
Dr Marleen Kunneman,
Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, Netherlands;
kunneman@lumc.nl

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For too many people, their care plans are designed without fully accounting for who they are, the lives they live, what matters to them or what they aspire to achieve. In other words, these care plans are designed for 'patients like this' rather than for 'this patient'. To improve this situation, investigators often propose interventions, such as patient decision aids or patient-reported experience measures, which may disrupt clinical practice and increase the work patients must do. These interventions 'target' patients, or rather the images, biomarkers, or numbers that represent their disease, rather than the person behind their patient role. Success becomes getting patients to use the interventions or to report high experience scores as they become overwhelmed by the work of accessing and using healthcare while completing self-care tasks.

Designing care that fits individual patients, requires patients (their loved ones) and clinicians to work together. For them to appreciate the situation of the patient, beyond its biology, and to respond to this situation by cocreating plans of work that make sense. This work of making care fit takes place mostly during clinical encounters at the point of care. As patients implement the plans in their personal environment, they work to make care fit at the point of life. The patient is usually the one person bridging these two worlds, and whatever is left undiscussed with their clinician at the point of care is also left unconsidered when designing care plans. This in turn leads to care plans patients do not need, understand or cannot implement at the point of life. This result is both wasteful and harmful.

In March 2021, 25 people from seven countries (online supplemental file 1) came together to identify and reflect on the necessary conditions for making care fit for each patient. Their position statement calls on clinicians, patient advocates, policy-makers, researchers and editors to work towards enabling and fostering efforts that make it easier for clinicians together with patients and their loved ones to make care fit.

Position statement

For care to fit, care should be:

- Maximally responsive to patients' unique situation. It should reflect each patient's personal and medical backstory, and life circumstances.
- Maximally supportive of patient priorities. It places patients' needs and wishes in the foreground, accounting for and supporting their capacity to cope, adapt and thrive. It is congruent with each patient's values and their goals for life, well-being and healthcare. It does not do harm. It draws from research evidence and guidelines for 'patients like this' to flexibly form care for 'this patient'. It knows that people vary in their valuation of life and of care.
- Minimally disruptive of patient lives. Through conversations, it understands that care contributes to how life is lived or aimed to be lived. It understands that patients have a finite and varying capacity to prevent disruption, to cope and to adapt.
- Minimally disruptive of patients' loved ones and social networks. It is inclusive of and flexibly supports each patient's community of care, including their loved ones. It is not bound by the healthcare setting, but instead respectfully enters the patient's life space to support the work that patients do both in and with their community to make care fit.

Making care fit:

- Requires patients (their loved ones) and clinicians to collaborate. They use person-sensitive communication, tailoring both the content and the manner of their conversation to their needs, abilities and to the situation. This conversation is potentially supported by tools. Care is built through equal patient–clinician relationships, mutual respect, willingness to accept each other's contributions, empathy, humanity and dignity.
- Is an ongoing and iterative process. People's needs, desires, capacities, capabilities and personal or medical situation may change. Care plans should therefore be flexible and continuously modified.

Although the object of making care fit is to advance the situation of patients, the consequences of caring impact positively on patients, their loved ones, clinicians and healthcare systems.

Faculty: Marleen Kunneman (kunneman@lumc.nl), Mara van Beusekom, Ingeborg Griffioen, Nanon Labrie.

Participants: Dominique Allwood, Martijn Bauer, Mara van Beusekom, Karen Buckley, Sean Dinneen, Jane Edgar, Stuart Grande, Derek Gravholt, Ingeborg Griffioen, Anne Haddow, Ian Hargraves, Marij Hillen, Síofra Kelleher, Martha Kidanemariam, Maria Kristiansen, Marleen Kunneman, Nanon Labrie, Sara Laurijssen, Victor Montori, Miranda Moskie, Floor van Nuenen, Viet-Thi Tran, Nicole van Veenendaal, Liesbeth van Vliet.

Collaborators: Erin Barreto, Rodney Mountain, David Vinkers, Moniek Voermans.

Author affiliations
[1]Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, The Netherlands
[2]Knowledge and Evaluation Research Unit, Mayo Clinic Rochester, Rochester, Minnesota, USA
[3]Faculty of Industrial Design Engineering, Delft University of Technology, Delft, Zuid-Holland, The Netherlands
[4]Department of Language, Literature & Communication, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands
[5]Department of Public Health & Center for Healthy Aging, University of Copenhagen, Kobenhavn, Denmark
[6]School of Medicine, University of St Andrews, St Andrews, UK

Twitter Marleen Kunneman @MarleenKunneman and Victor M Montori @vmontori

Collaborators Making Care Fit Working Group (alphabetical order):Dominique Allwood, Martijn Bauer, Mara van Beusekom, Karen Buckley, Sean Dinneen, Jane Edgar, Stuart Grande, Derek Gravholt, Ingeborg Griffioen, Anne Haddow, Ian Hargraves, Marij Hillen, Síofra Kelleher, Martha Kidanemariam, Maria Kristiansen, Marleen Kunneman, Nanon Labrie, Sara Laurijssen, Victor Montori, Miranda Moskie, Floor van Nuenen, Viet-Thi Tran, Nicole van Veenendaal, Liesbeth van Vliet.

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ORCID iD
Marleen Kunneman http://orcid.org/0000-0001-5334-1085

SUPPLEMENT TO 'MAKING CARE FIT MANIFESTO': APPROACH

Setting

The online 'Making care fit partnership' meeting took place on March 4th and March 11th 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 pomp 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.