

# 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

10.1136/bmjebm-2021-111871

► Additional supplemental material is published online only. To view, please visit the journal online (http://dx.doi.org/10.1136/bmjebm-2021-111871).

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

Check for updates

<sup>®</sup> Author(s) (or their employer(s)) 2021. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Kunneman M, Griffioen IPM, Labrie NHM, et al. BMJ Evidence-Based Medicine Epub ahead of print: [please include Day Month Year]. doi:10.1136/ bmjebm-2021-111871 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.

# EBM opinion and debate

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

#### Author affiliations

<sup>1</sup>Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, The Netherlands

<sup>2</sup>Knowledge and Evaluation Research Unit, Mayo Clinic Rochester, Rochester, Minnesota, USA

<sup>3</sup>Faculty of Industrial Design Engineering, Delft University of Technology, Delft, Zuid-Holland, The Netherlands

<sup>4</sup>Department of Language, Literature & Communication, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands

<sup>5</sup>Department of Public Health & Center for Healthy Aging, University of Copenhagen, Kobenhavn, Denmark

<sup>6</sup>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.

Contributors MKunneman secured funding, organised the meeting, drafted the manuscript and approved the final version. IPMG organised the meeting, drafted the manuscript and approved the final version. NHML organised the meeting, provided edits to the manuscript and approved the final version. MKristiansen organised the meeting, provided edits to the manuscript and approved the final version. VM organised the meeting, provided edits to the manuscript and approved the final version. MMvB organised the meeting, drafted the manuscript and approved the final version.

Funding This work was supported by the Royal Netherlands Academy of Arts and Sciences (KNAW) & Dutch Research Council (NWO) The Netherlands Organisation for Health Research and Development (ZonMw) (016.196.138).

Competing interests None declared.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; internally peer reviewed.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

### ORCID iD

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