

Implementing structured follow-up of neonatal and paediatric patients: an evaluation of three university hospital case studies using the FRAM

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Introductions

Leren van het 'Follow Me' programma



Véronique Bos doet als promovendus onderzoek naar projecten gericht op zorgvernieuwing. Zij maakt deel uit van het Europese Marie Skłodowska-Curie training netwerk HealthPros (www.healthpros-h2020.eu), gecoördineerd vanuit de afdeling Sociale Geneeskunde in het AMC. Zij gebruikt hierbij haar ervaring vanuit operationeel management en kwaliteitsbeleid in ziekenhuizen. Binnen haar project onderzoekt zij het Follow Me programma van de Kinderchirurgie, IC-Kind en IC-Neonatologie. Zij zal betrokkenen interviewen en observaties doen bij de MDO's. Vragen? Contact Véronique Bos: v.l.bos@amsterdamumc.nl.

The Background

What's happening with our children after survival?



One Follow Me vision – implementation in three departments

Table 1 Case study descriptions

Case study/ department	Follow Me programme launched	Outpatient follow-up time points or ages ^a	Number of clinical patients treated in 2019	Number of unique patients with an appointment in the follow-up programme in 2019
Neonatal ICUs	2020	6, 12 and 24 months and 5 and 8 years of age	Location AMC: ~400 unique neonates Location VUMC: ~360 unique neonates	Location AMC: ~500 ^b Location VUMC: ~250 ^b
Paediatric ICU	March 2018	3-to-6 and 12 months after ICU discharge; 6 years of age	564	92
Paediatric surgery department	October 2017	6, 12 and 24 months and 5, 6, 8, 12 and 16 ^c years of age	46 infants born with congenital disorders in 2019	94

^a follow-up time points were chosen in accordance to research (e.g. PICU time point 6 years of age due to validity of lung tests), national standards (e.g. NICU time points), important steps in motor development (e.g. time point 12 months learning to walk) and patient or their families need (e.g. time point 6 years of age transition to school). ^bChildren in follow-up before the Follow Me programme was launched ^c Before 2019, age 17

The Research

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Aim	To learn from daily practice and to improve the quality and sustainability of the follow-up programmes as well as their impact on clinical practice.
Research objective	To evaluate the implementation of the outpatient follow-up programmes of the neonatal ICUs, paediatric ICU and paediatric surgery departments by comparing work in practice (work-as-done), with the mission, vision, organisational blueprint and tools established by the management team of the Follow Me programme (work-as-imagined).
Research Q's	<ol style="list-style-type: none">1. How is the implemented follow-up programme (a) generating data collection and standardisation for the measurement of long-term outcomes, (b) allocating key stakeholder roles and responsibilities, and (c) building control and feedback loops to aid decision-making?2. Can gaps between work-as-imagined and work-as-done be identified in the three case studies and, if so, how could such gaps be overcome using within- and cross-case-study learning?
Methods FRAM	Documentary analysis Semi-structured interviews Observations and feedback sessions

Lots of FRAM models

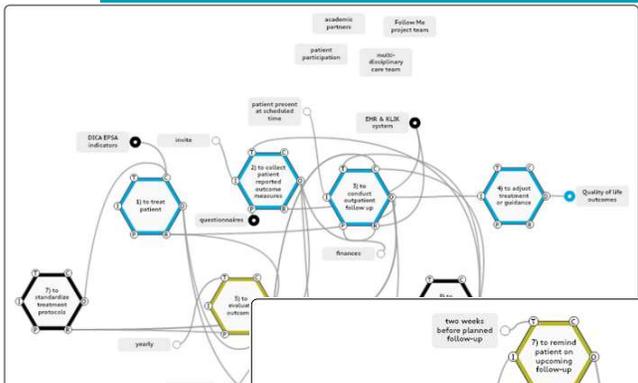


Fig. 2 Work-as-imagined model Follow Me programme. feedback loops. Key stakeholders are extracted from the

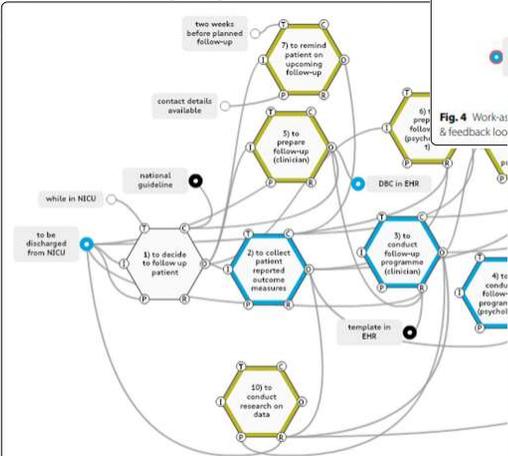


Fig. 3 Work-as-done model neonatal ICU, location AMC. Blue: data collection, black: standardization of treatment and follow-up, yellow: controls & feedback loops. Key stakeholders are extracted from the model and shown separately in the top right corner

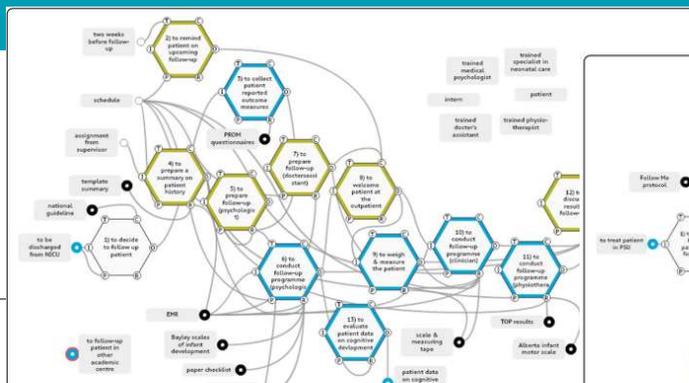


Fig. 4 Work-as-done model paediatric ICU. Blue: data collection, black: standardization of treatment and follow-up, yellow: controls & feedback loops. Key stakeholders are extracted from the model and shown separately in the top right corner

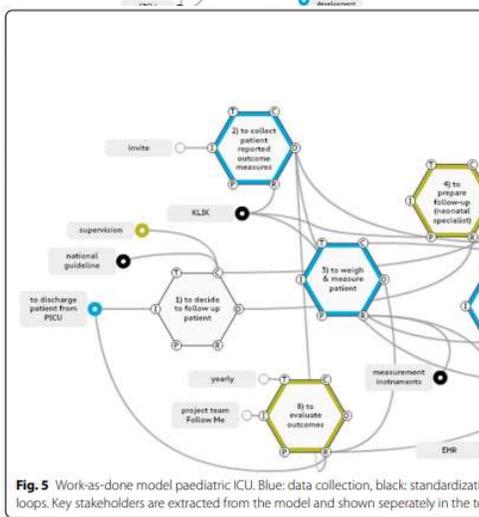


Fig. 5 Work-as-done model paediatric ICU. Blue: data collection, black: standardization of treatment and follow-up, yellow: controls & feedback loops. Key stakeholders are extracted from the model and shown separately in the top right corner

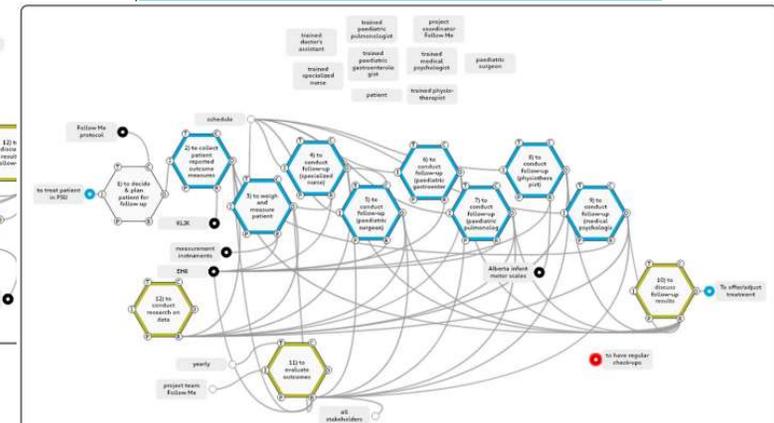


Fig. 6 Work-as-done model paediatric surgery department. Blue: data collection, black: standardization of treatment and follow-up, yellow: controls & feedback loops. Key stakeholders are extracted from the model and shown separately above the model

Results from talking agreeing opportunities disagreeing discussing limits

MDT

We saw big variety in multidisciplinary teams – the who – the what – the how – the feels.
AND: that's OK!

Data

Collection & use fragmented **from a patient perspective**. Examples: parents wondering what questionnaire? I filled out a questionnaire on my psychosocial function – which doctor?

Purpose

To include timely actionable indicators to measure effectiveness and performance of the follow-up programme itself

Thank you

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