SELF-MADE & SOUND

e-health programmes for patients with chronic conditions

2012 - 2017

Betsie.vanGaal@Radboudumc.nl

Radboud university medical center, the Netherlands   6 October 2016

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ZonMw

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Self-Made & Sound

Aims - to contribute to the knowledge on self-management programmes for patients with chronic conditions

- Tailored to the needs of the patients
- Delivered via e-health

Examine the boundaries of the e-health self-management support programmes

Self-Made & Sound

Patient groups
- Rheumatoid Arthritis
- Cardiovascular Risk
- Severe Mental Illness
- Chronic kidney disease

Reumatoid Arthritis

Mapping

Early trials

Four junior researchers Nijmegen

Chronick Kidney Disease

Intervention

Self-management

The Netherlands

Severe Mental Illness

NURSING SCIENCE

patient oriented development

Cardio Vasculair Risk

Process evaluation

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Collaboration

Patient groups
- Rheumatoid Arthritis
- Cardiovascular Risk
- Severe Mental Illness
- Chronic kidney disease

Health care settings
- Radboudumc
- Sint Maartenskliniek
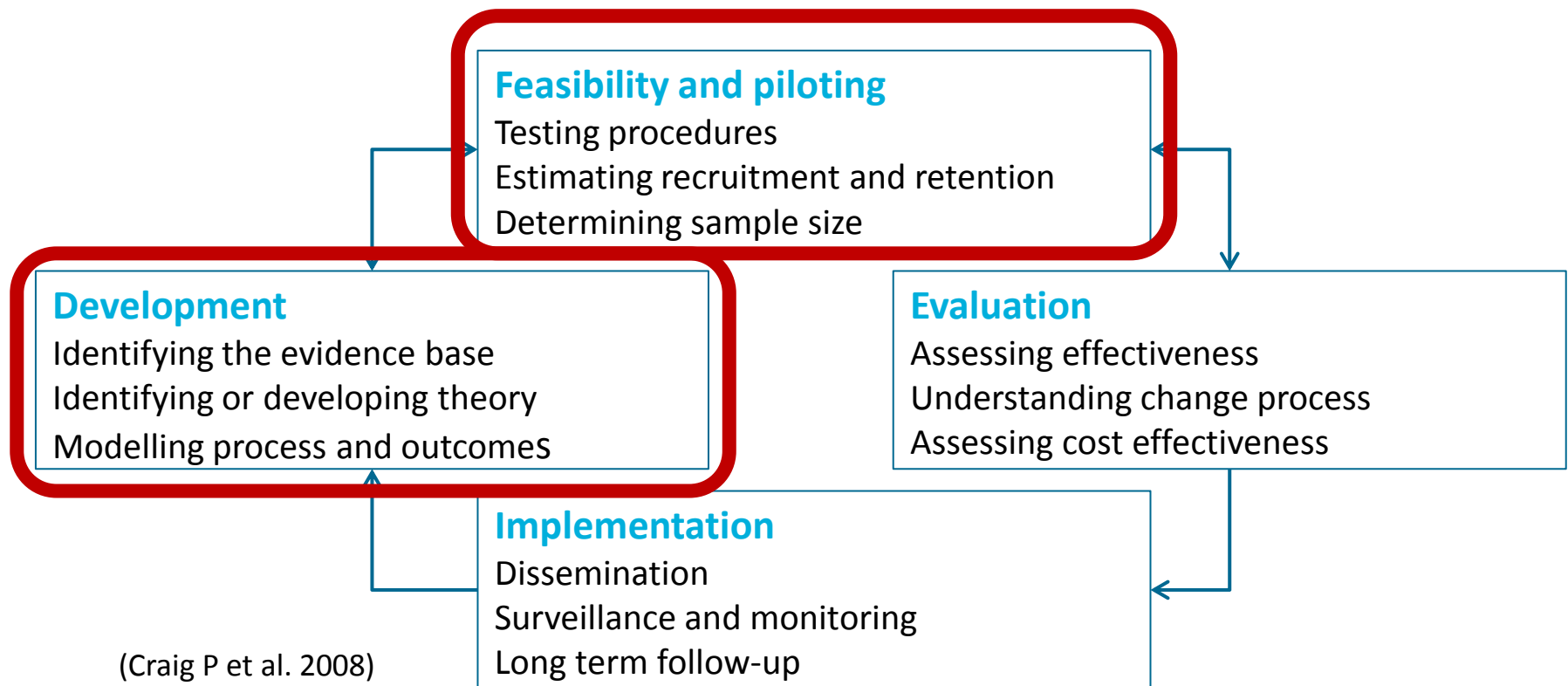- Bernhoven hospital
- Dimence

Universities
- Han University of Applied Sciences
- Saxion University of Applied Sciences
- Indiana University Perdue University Indianapolis
- University of Glasgow
- Dalhousie University, Halifax

Development of a complex intervention

MRC Framework

Feasibility and piloting
Testing procedures
Estimating recruitment and retention
Determining sample size

Development
Identifying the evidence base
Identifying or developing theory
Modelling process and outcomes

Evaluation
Assessing effectiveness
Understanding change process
Assessing cost effectiveness

Implementation
Dissemination
Surveillance and monitoring
Long term follow-up

(Craig P et al. 2008)

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Self-Made & Sound – 4 patient groups

The development: Intervention Mapping

- A systematic framework for the development and implementation of health promotion programmes[1,2]
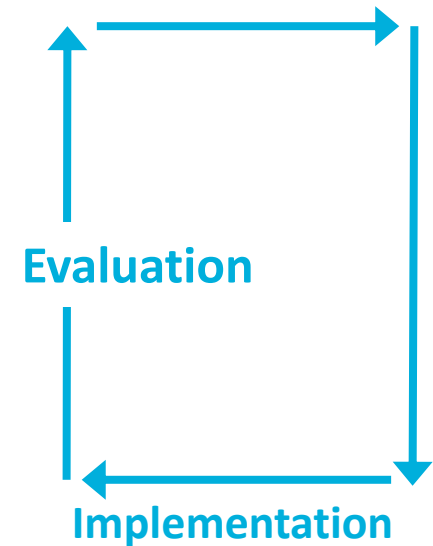
- 6 steps
  1. Needs assessment
  2. Program objectives
  3. Selection of theory & strategies
 4. Program components
  5. Implementation
  6. Evaluation

Evaluation

Implementation

- A development group with: 4 – 7 patients / 5 – 6 professionals & 3 project members
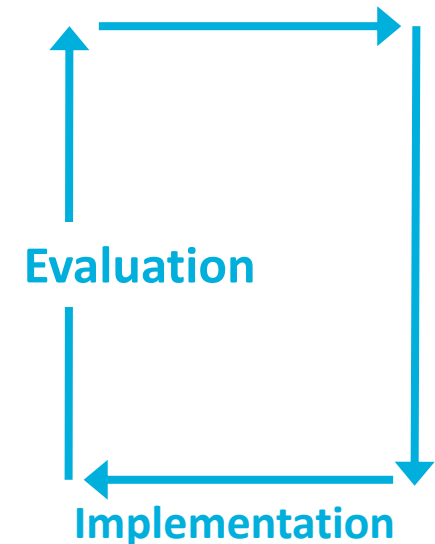
1. Bartholomew LK et al. (1998); 2. Bartholomew LK et al. (2011)

We present…

- …the first 3 steps of intervention mapping

1. Needs assessment
2. Program objectives
3. Selection of theory & strategies
4. Program components
5. Implementation
6. Evaluation

Evaluation
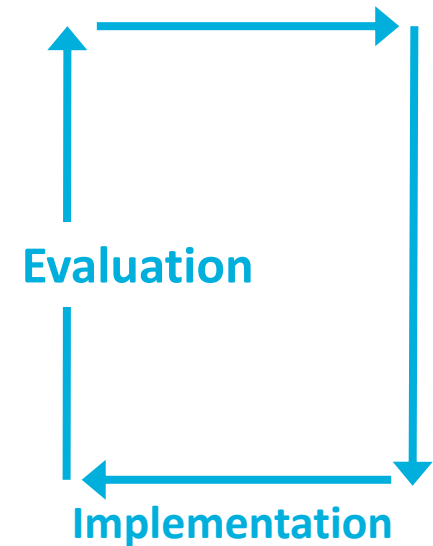
Implementation

We present…

- …how we have created and implemented the programmes

1. Needs assessment
2. Program objectives
3. Selection of theory & strategies
4. Program components
5. Implementation
6. Evaluation

Evaluation

Implementation

We present…

- …the evaluation with the preliminary results of the rheumatoid arthritis programme
  1. Needs assessment
  2. Program objectives
  3. Selection of theory & strategies
  4. Program components
  5. Implementation
  6. Evaluation

Evaluation

Implementation
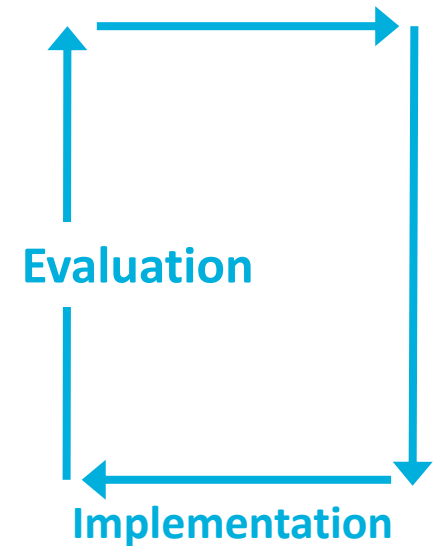
Self-Made & Sound Project

Development and testing of the tailored web-based self-management support program 'Vascular View'

Saskia Puijk-Hekman   6 October 2016

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The 'Vascular View' Programme

Objectives

- To empower patients to self-manage their CVD

- To improve quality of life among patients with CVD

Self-Management

- What do you mean by self-management?

Instructions
- 1. Grab your phone
- 2. Go to www.menti.com
- 3. Enter the code 77 79 81 and vote!

Self-Management

"Self-management is an individual's ability to manage the <u>symptoms</u>, <u>treatment</u>, <u>physical</u> and <u>psychological consequences</u> and <u>lifestyle changes</u> inherent in living with a chronic condition".

According P. McGowan, 2005 and J. Barlow et al, 2002.

Intervention Mapping

- A systematic framework for the development and implementation of health promotion programmes[1,2]

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1. Bartholomew LK et al. Intervention mapping: a process for developing theory- and evidence based health education programs. (1998).
2. Bartholomew LK et al. Planning health promotion programmes: an intervention mapping approach. (2011)

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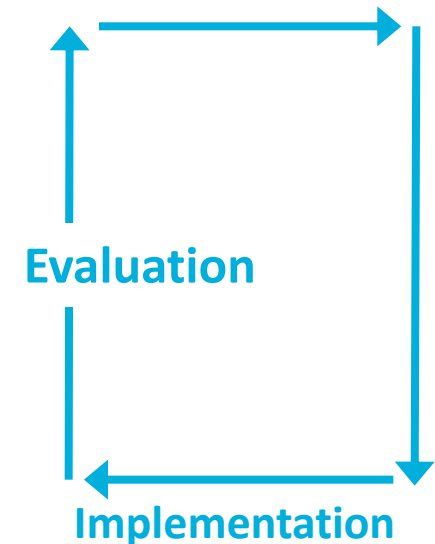
Development Group CVD

Patient Development Group	Professional Development Group
- 1 female - 6 males	- Medical specialist in general and vascular medicine - Neurology nurse - Cardiology nurse - Vascular surgery nurse - Psychologist - Dietician - Physical therapist

Step 1 Needs assessment

- Literature review: What are patients' experienced problems and (support) needs for self-management and their determinants

- Choose the most important health problems – related needs and their impact on quality of life

- Discussion in the development groups

Step 1 Needs assessment (2)

Problems & Determinants

- **Physical**
  Obesity, fatigue, pain, sexual dysfunction
- **Psychological**
  Fear, stress, depressive feelings
- **Treatment**
  Interacting with professionals, medication non-adherence
- **Lifestyle changes**
  Unhealthy nutrition, physical inactivity
- **Daily life**
  Setting boundaries, coping with changed role in family, job and society

1. Knowledge
2. Awareness
3. Risk perception
4. Attitude
5. Self-efficacy
6. Subjective norm
7. Motivation (intention)
8. Habits

e-health
VAAT IN ZICHT

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Example

- **Problem**:
Experienced (changed) boundaries in daily life

- **Behaviour**:
to set (changed) boundaries in daily life

- **Determinants**:
knowledge, awareness, attitude, subjective norm, self-efficacy

Step 2 Objectives

- Subdivide selected health problems and support needs from step 1 into objectives

- Combine objectives with relevant determinants into sub-objectives

- Theory: I-Change Model 2.0[1]

- Discussion in the development groups

1. de Vries H, Kremers SP, Smeets T, Brug J, Eijmael K. The effectiveness of tailored feedback and action plans in an intervention addressing multiple health behaviors. (2008).

I-Change model[1]
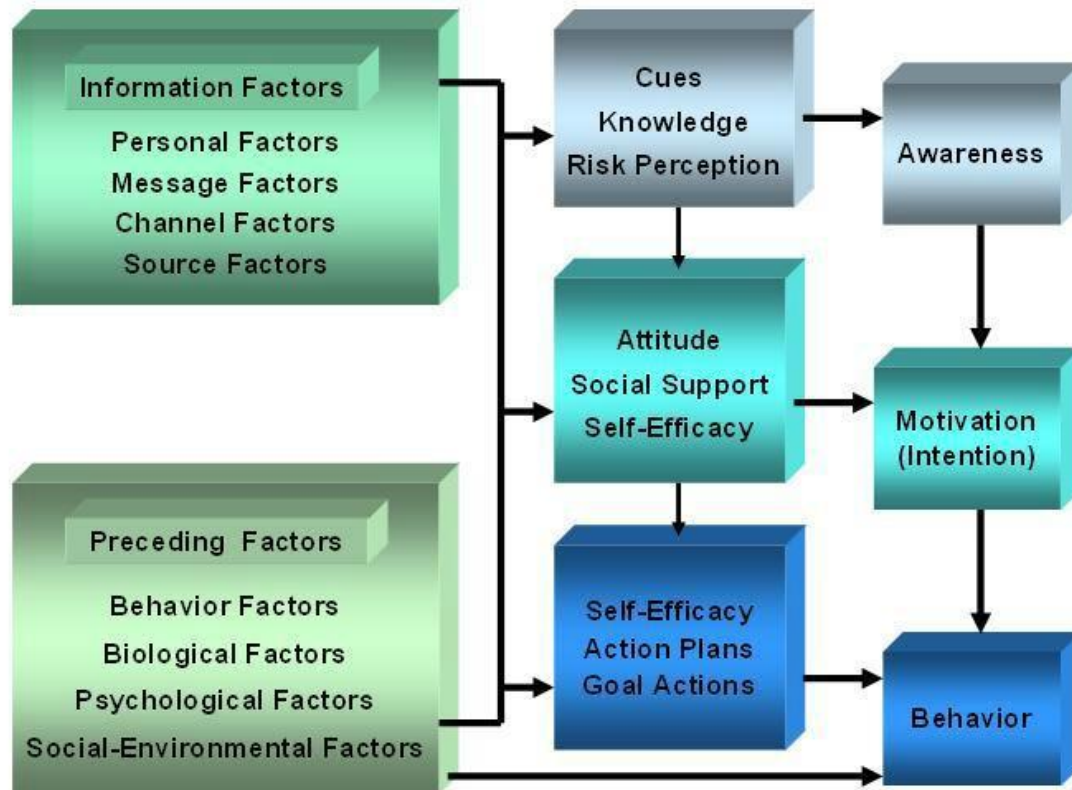
1. de Vries H, Kremers SP, Smeets T, Brug J, Eijmael K. The effectiveness of tailored feedback and action plans in an intervention addressing multiple health behaviors. (2008).

Selected topics

- Lifestyle (nutrition, physical activity, smoking and use of alcohol)
- Setting boundaries
- Medication adherence
- Emotions (fear)
- Interaction with the health professional

Step 3 Theory

- Choose theories & strategies to change patient behaviour – Behaviour Change Techniques (BCT)[1,2]
- Select intervention methods
- Develop practical applications
- Discussion in the development groups

1. Abraham C., Michie S. A taxonomy of behavior change techniques used in interventions. The coding manual. (2008)
2. De Bruin M., Kok G. et al. Coding maual for behavioral change techniques. (2007)

Behaviour change techniques (BCT)

Objective: Patients need to set boundaries

Knowledge
- BCT: General information

Awareness
- BCT: Self-monitoring

Attitude
- BCT: Persuasive communication

Behaviour change techniques (BCT)

How do you increase patient's confidence about setting

boundaries (self-efficacy)?

o Modelling
o Setting graded tasks
o Goal setting
o All three strategies can be used

Go to www.menti.com, enter the code 77 79 81 and vote!

Practical applications

Objective: Patients need to set boundaries

Practical applications – Setting boundaries

e-health program 'Vascular View'
- Screening, monitoring and tailored feedback
- General and persuasive information
- Tailored exercises
- Peers telling (video) their experiences – what helped them & what where pitfalls
- Goal-setting

Summary

- **Theoretical background of 'Vascular View'**

  Step 1 Needs assessment

  Step 2 Objectives

  Step 3 Theory

Intervention Mapping step 4 & 5

Titus Beentjes
2016 October 06

Intervention Mapping

- A systematic framework for the development and implementation of health promotion programs[1,2]

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  5. **Implementation**
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Evaluation

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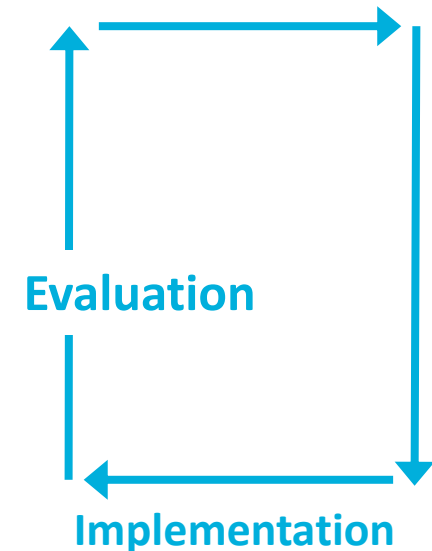
step 4. Program components

Building e-health applications based on:

- Patients preferences and interaction with professionals
- Selected strategies (BCT's) in step 3

step 4. Program components

- Incorporate selected strategies into an e-health platform

- Choosing a platform partner:
  - ✓ Ability to deliver desired strategies
  - ✓ Certified privacy protected platform
  - ✓ Ability to provide login data

step 4. Program components

Building 4 interventions for 4 different populations:

- 2 Non-guided training modules for people with
  - ✓ Rheumatoid Arthritis
  - ✓ Cardiovascular Diseases
- Multi component intervention including a non-guided training modules for parent of children with a chronic kidney disease
- Guided/blended training modules for people with Severe Mental Illness

Two non-guided intervention

For people with Rheumatoid Arthritis & Vascular Risk

- No opportunity to communicate with professional

- Welcome module: How does this intervention work

- Questionnaire: Assessing the need for specific training

- Online training modules, divided in sessions

- Monitoring module (diaries)

Multicomponent / Non-guided intervention

For Parents of children with a chronic Kidney disease

e-Powered Parents[1] consist of:

- o Information: Video's, News, Guidelines
- o Interactive: chat, forum, blog, private conversations
- o Non-guided training modules:
  - ✓ Communication
  - ✓ Setting boundaries
  - ✓ Stress-management
  - ✓ Coping with emotions

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e-Powered Parents[1]

1. e-Powered Parents is in collaboration with the Dutch Kidney Foundation

e-IMR
ILLNESS MANAGEMENT & RECOVERY 3[1]
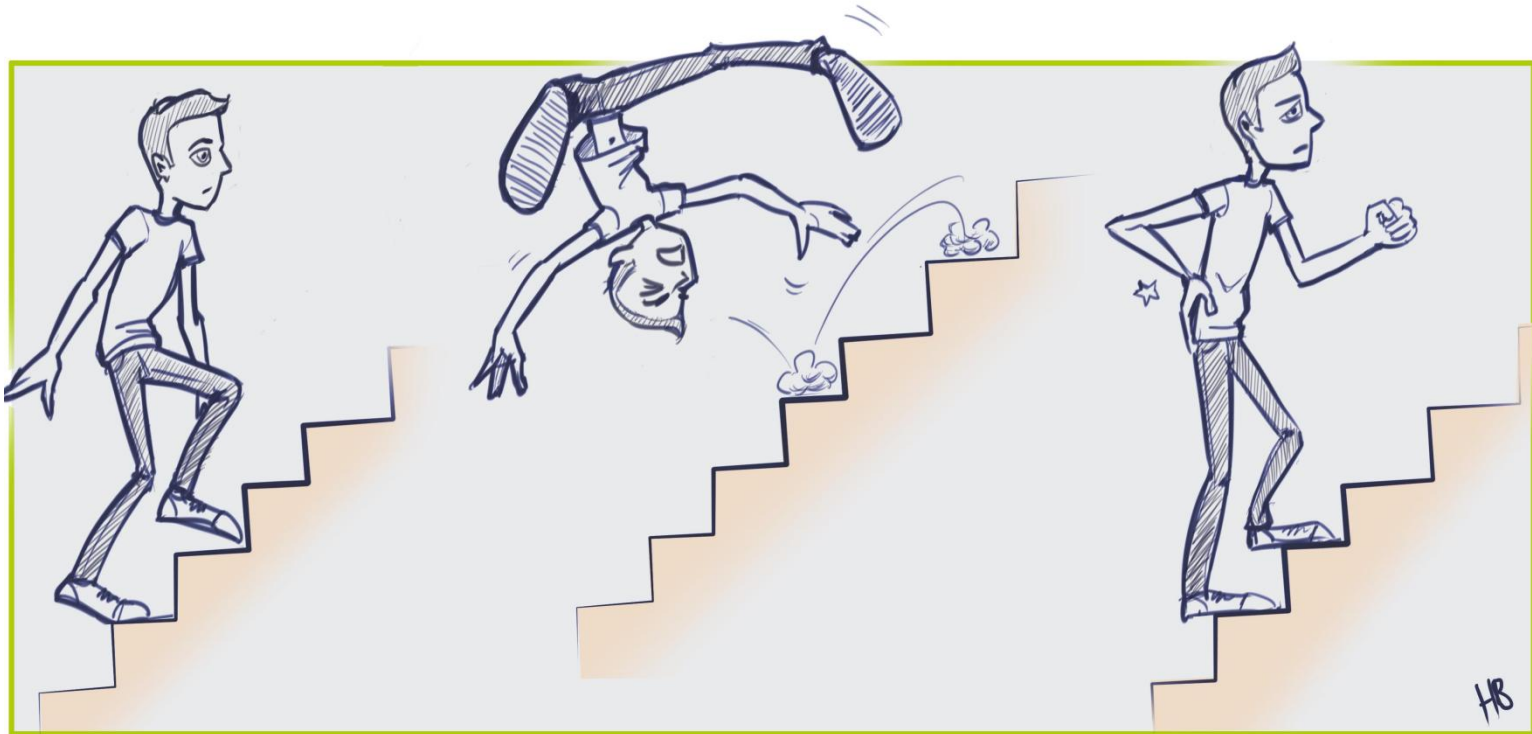
1. Gingerich , Mueser (2011), Illness Management & Recovery, Personalized Skills and Strategies for those with Mental Illness, implementation Guide, Hazelden, Dartmouth, USA.

Illness Management & Recovery

For people with Severe Mental Illness.

IMR Programme[1]: group or individual sessions using a paper textbook with 11 Modules:

1. Recovery strategies
2. Practical facts about mental illnesses
3. Stress-Vulnerability Model
4. Building social support
5. Using medication effectively
6. Drug & Alcohol use

7. Relapse prevention plan
8. Coping with stress
9. Coping with persistent symptoms
10. Getting your needs met in mental health system
11. Healthy lifestyles

1. Gingerich , Mueser (2011), Illness Management & Recovery, Personalized Skills and Strategies for those with Mental Illness, implementation Guide, Hazelden, Dartmouth, USA.

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Blending face to face & online

- Parallel online modules and the modules during the face to face sessions.

- Possibility to communicate with trainers between the face to face session

- Discussing online content during face to face sessions

- Option: communication between participants

e-IMR applications

- Peer testimonials
- Worksheets
- Personal goal tracking sheets
- Problem solving sheets
- Tracking successful coping strategies
- Relapse prevention plan
- Monitoring symptoms

Design e-IMR applications

According the Flat Explicit Design Model[1]:

- Singular focus;

- Simple architecture;

- Prominent contents;

- Explicit navigation;

- Inclusive hyperlink.

- Avoiding: mandatory fields; scrolling; large texts

1. Rotondi et al., *Critical Design Elements of E-Health Applications for Users With Severe Mental Illness: Singular Focus, Simple Architecture, Prominent Contents, Explicit Navigation, and Inclusive Hyperlink (2015)*

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e-IMR applications

- Peer testimonials
- Worksheets
- Personal goal tracking sheets
- Problem solving sheets
- Tracking successful coping strategies
- Relapse prevention plan
- Monitoring symptoms

Personal goal tracking sheet

e-IMR

minddistrict

titus beentjes 00.0.00 ▾

- 🎯 Start
- ☑️ Taken   **4**
- 💬 Gesprekken
- 👥 Contactpersonen
- 🔶 Module ▾
- 🔁 Terugvalpreventieplan ▾
- 📈 Monitoring ▾

Mijn IMR-Doelen

My personal recovery goal:

Recovery goal	Achievement
1. Going back to school in 2020	In progress ⬍ ❌
2. Restore relation with my family	In progress ⬍ ❌

Add a new goal

💡 U kunt uw persoonlijke hersteldoel aanpassen of veranderen. U kunt ook een nieuw persoonlijk hersteldoel toevoegen. Klik hiervoor op 'toevoegen'.

Personal goal tracking sheet

e-IMR

minddistrict   titus beentjes 00.0.00 ▾

- Start
- Taken **4**
- Gesprekken
- Contactpersonen
- **Module** ▾
- Terugvalpreventieplan ▾
- **Monitoring** ▾

My short term recovery goals:

Short term goal	Attainable steps	Achievement
1.1 restore daily rhythm 1.2 visiting day-center daily	1.1 in bed between 10;30 PM and 8:30 AM 1.2 visiting day-center on Wednesday during four weeks	Accomplished ⬍ ✖
2.1 visiting my sister 2.2 visiting my farther 2.3 visiting my mother	2.1 calling my sister 2.1 meeting her in the park 2.2 the same order	In progress ⬍ ✖

Add a new goal

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Monitoring symptoms

Monitor your symptoms

What are you going to do

Tijdens de e-IMR training vult u elke week deze vragenlijst in. Zo houdt u online bij hoeveel last u heeft van uw symptomen. Nadat u de online vragenlijst hebt ingevuld en opgestuurd, kunt u uw vooruitgang in een grafiek bekijken. Zo krijgt u een helder beeld beeld van hoe het er voor staat.

💡 U krijgt bericht wanneer het tijd is om een nieuwe vragenlijst in te vullen. Probeer uw gegevens elke week op een vast tijdstip in te vullen.

How to fill in the questionnaire

Hieronder staan 8 symptomen. Onder elk symptoom staat een korte uitleg. Zo weet u wat er met dit symptoom bedoeld wordt. Geef bij elk symptoom aan hoeveel last u hier de afgelopen week van had. Dit doet u met een score van 0 tot 5.
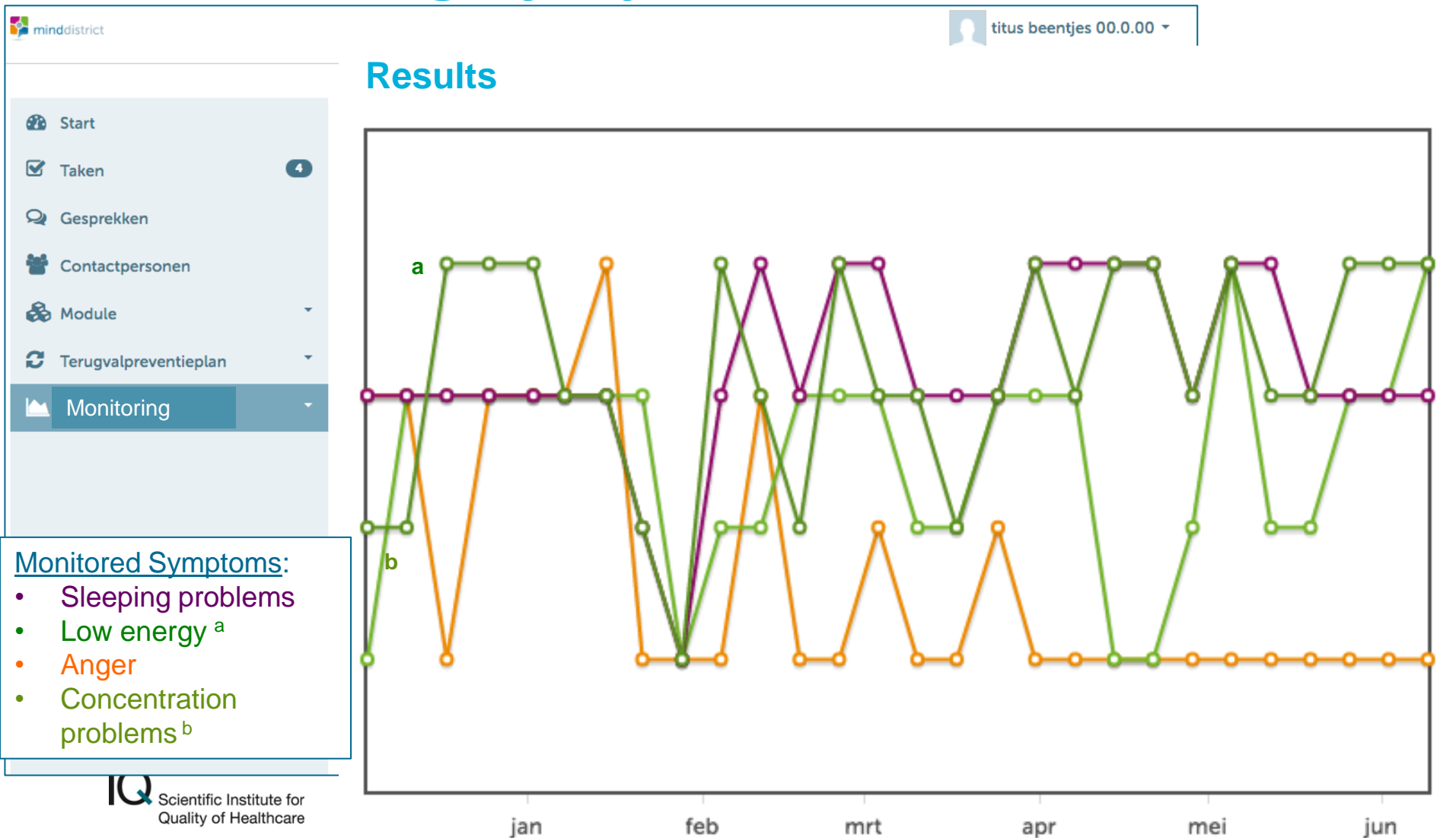
Monitoring symptoms

Other Symptoms:
- Hallucinations
- Delusions
- Sleeping problems
- Low energy
- Anger
- Concentration problems

Monitoring symptoms

Intervention Mapping

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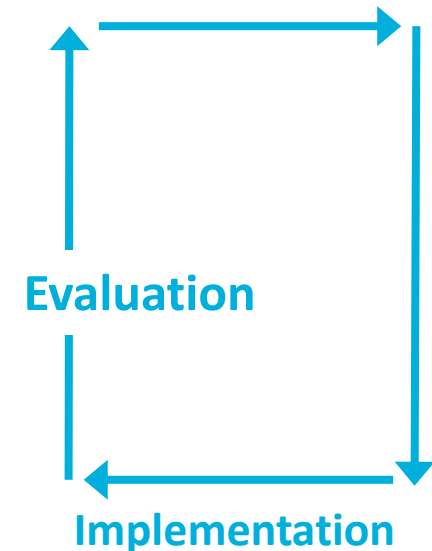
1. Bartholomew LK et al. Intervention mapping: a process for developing theory- and evidence based health education programs. (1998).
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Step 5. Implementation

- Plan for program adoption, implementation, and sustainability

- Factors for adoption of e-IMR in participants:
  - ✓ Cognitive impairments
  - ✓ Computer literacy
  - ✓ Access to a computer

Step 5. Plan for programme adoption

- Eligible institutions from the Dutch IMR-network

- Factors for adoption of e-IMR in trainers/institutions:
  - ✓ Access to a computer / wifi at the location / audio board
  - ✓ Over protected computers/email

Step 5. Plan for programme adoption

- Implementation strategies:
  - ✓ Assessment of computer literacy/availability
  - ✓ Assessing the need for computer support (bachelor students)

  - ✓ Talks with trainers about what participants need to start using the e-IMR

Step 5. Plan for programme adoption

- Implementation strategies from all the programmes:
  - ✓ Informing professionals
  - ✓ Introducing the intervention
  - ✓ User guidelines
  - ✓ Reminders
  - ✓ News letters

Summary

- Showed the differences in our 4 interventions

- Showed some of the programme components

- Overview of strategies to adopt the programme in a pilot project

Questions ??

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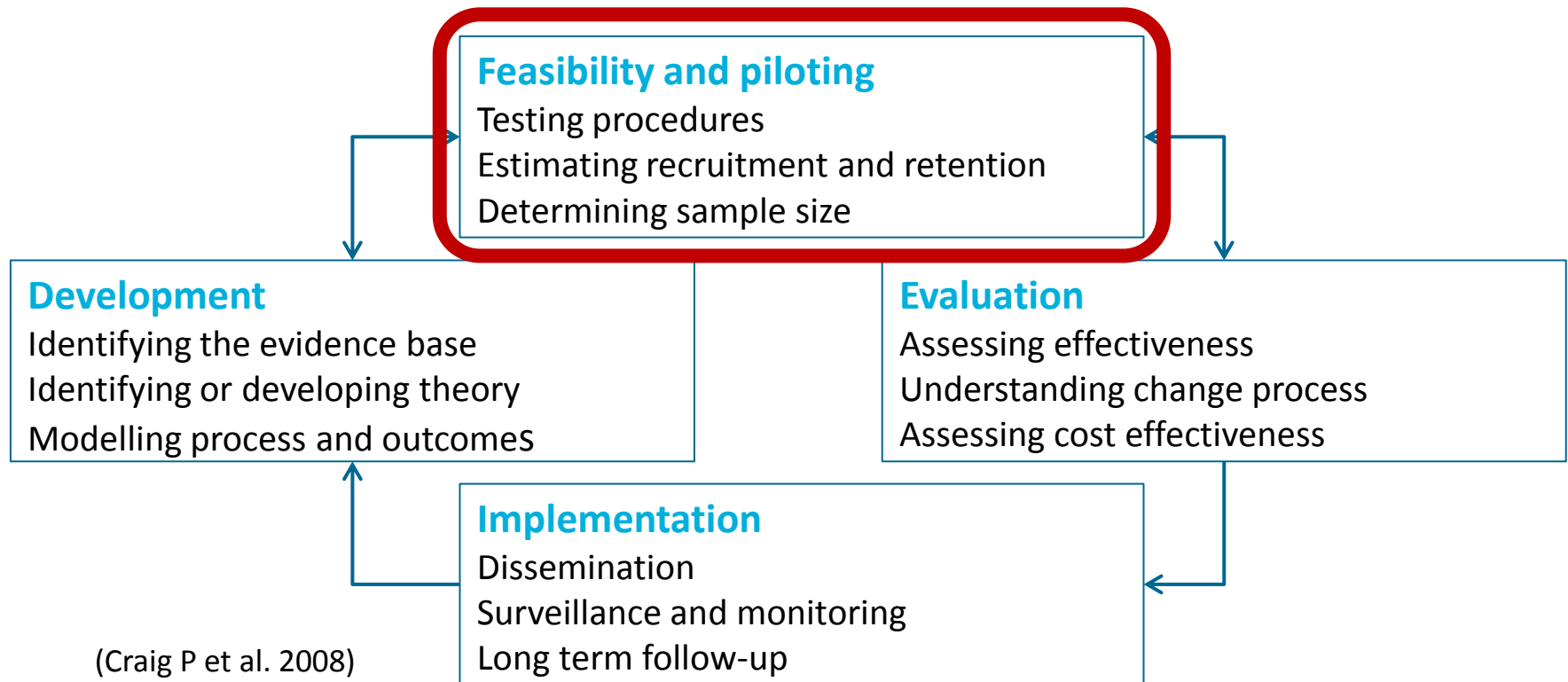# An e-health Self-Management programme for patients with Rheumatoid Arthritis

The evaluation

Rixt Zuidema presented by Betsie van Gaal
**Radboud university medical center, the Netherlands**

6 October 2016

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Quality of Healthcare

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Development of a complex intervention

MRC Framework

Feasibility and piloting
Testing procedures
Estimating recruitment and retention
Determining sample size

Development
Identifying the evidence base
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Evaluation
Assessing effectiveness
Understanding change process
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Implementation
Dissemination
Surveillance and monitoring
Long term follow-up

(Craig P et al. 2008)

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Intervention Mapping

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  6. **Evaluation**

Evaluation

Implementation

- A development group with 5 RA patients / 5 RA health care professionals & 3 project members
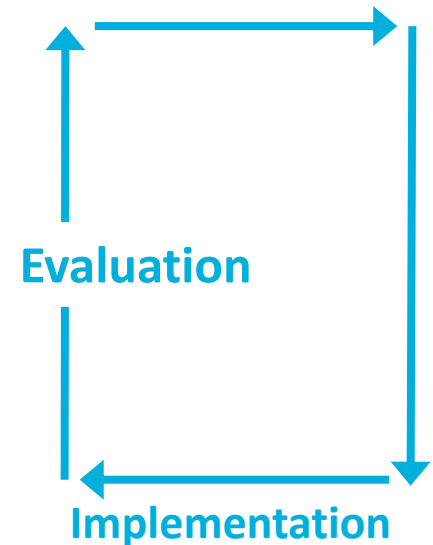
Step 6 Evaluation

- Pilot to identify the most appropriate outcome for the online self-management programmes

- A process evaluation to examine the usability of the programmes

Step 6 Evaluation

- Design – pilot trials

- Population & sample – 200 patients/parents

Outcomes	RA	CVR	SMI
General	Patient characteristics Patient Activation Measure (PAM 13) Quality of Life (Rand 36)		
Specific	SMAS-S PEPPI-5 MPCI-F RASE	PEPPI-5 LSQ CSES MMAS-8 BMQ	BSI IMR-scales MANSA MHRM
Process	Actual participation in the intervention & feasibility		

Step 6 Evaluation (2)

- Pilot RCT
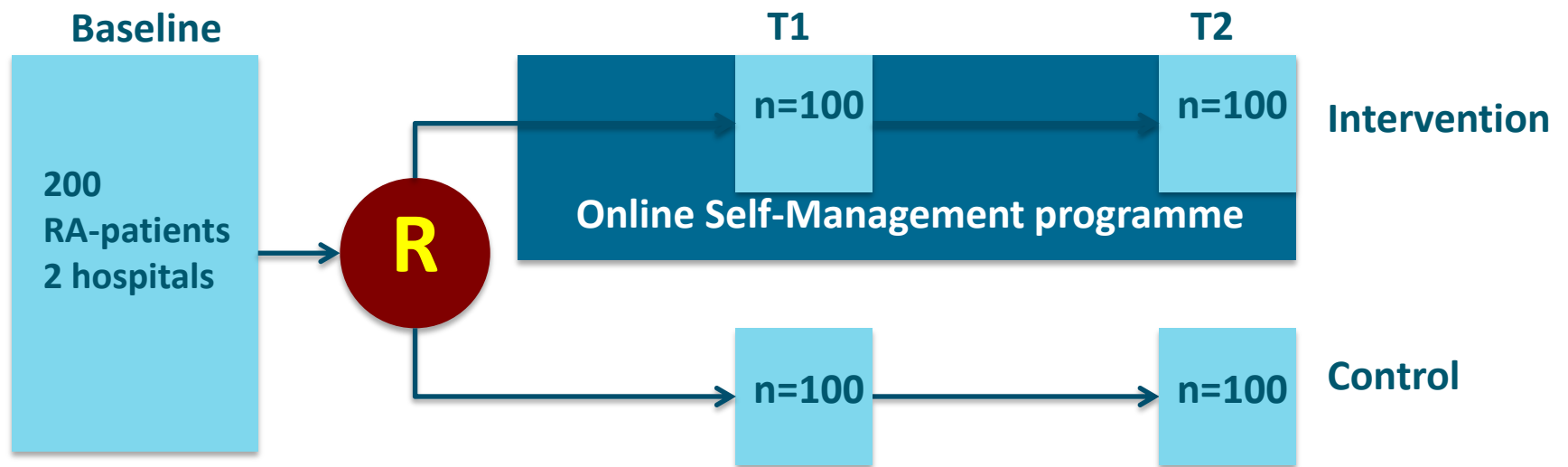
Methods – outcomes RA

Outcomes	Instruments
Quality of life	Rand 36
Self-management behaviour	PAM-13
	SMAS-S
Focus on fatigue	MPCI-F
Self-efficacy	RASE
	PEPPI-5

Methods – process evaluation

Key components[1]	
Recruitment	The used procedure to approach and attract patients
Fidelity	% patients to which the program was delivered
Dose delivered	Delivery of the programme with the courses
Dose received	The use of the courses in the programme & satisfaction
Reach	% patients that used the programme
Context	Influencing factors

1 Steckler & Linnan (2002)

Methods – data collection & analyses

	Questionnaire	Interview
Patient characteristics	Baseline	
Outcomes	Baseline – 6 – 12 months	
Satisfaction & experience	6 – 12 months	12 months
Login data	6 – 12 months	

- Mixed model with repeated measures

- Qualitative analyses

Results – population

Eligible RA patients n =189
Hospital 1 n = 90
Hospital 2 n = 99

83% response questionnaire
Hospital 1 n = 74
Hospital 2 n = 83

R

Usual care n=79

Intervention n=78

Follow-up

T1: n =74

T1: n =58

T2: n =73

T2 n =54

Analyses

n=73

n=54
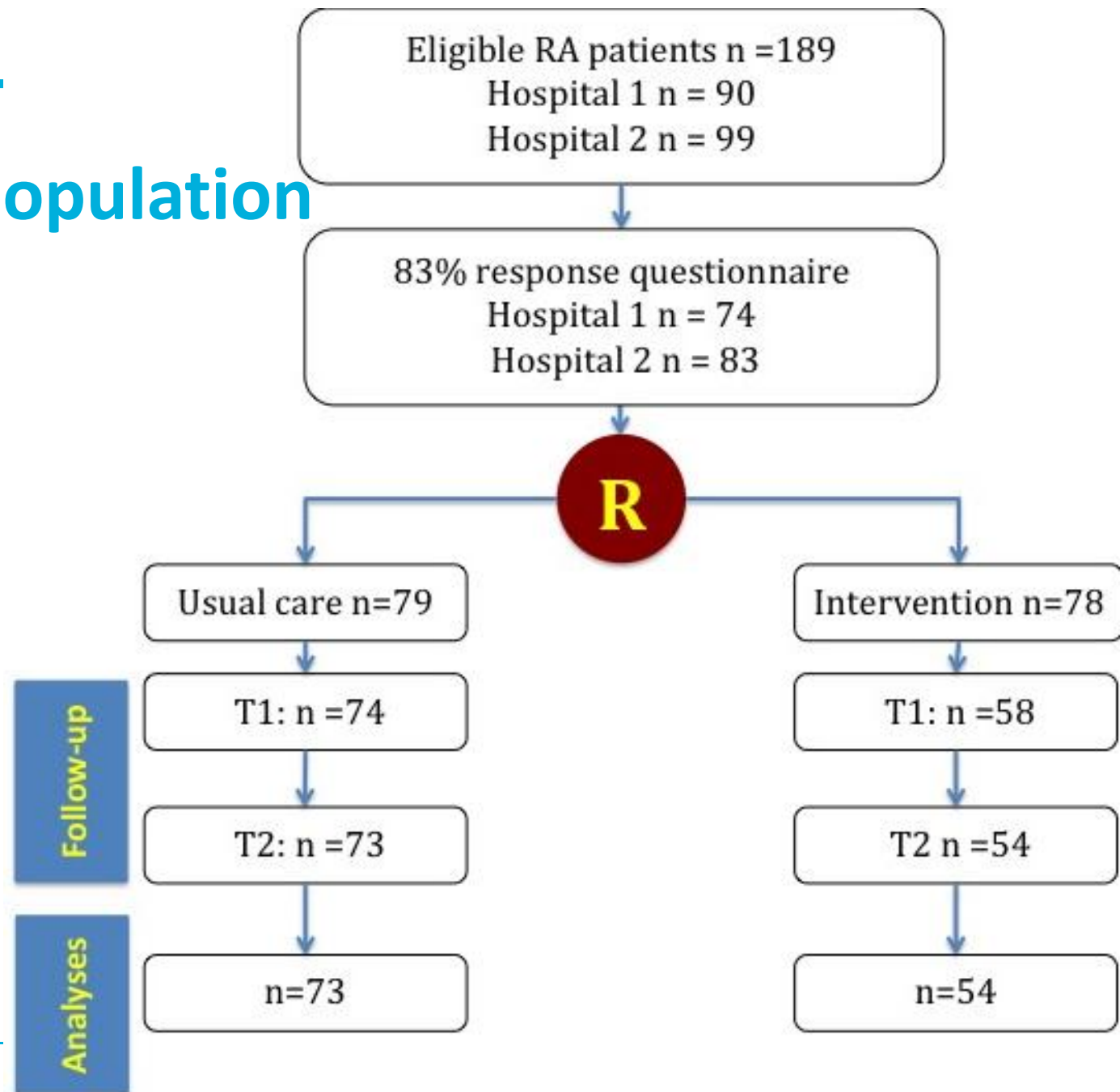
Results – who are the participants?

Baseline (T0)	Usual Care	Intervention
Women, n (%)	52 (66%)	51 (65%)
Age, mean in yrs (SD)	63 (10.22)	61 (11.34)
RA since, mean in yrs (SD)	17 (11.33)	14 (11.40)
Educational level n (%)		
Low	28 (35%)	10 (13%)
Medium	28 (35%)	43 (55%)
High	23 (29%)	25 (32%)

Results – Quality of life
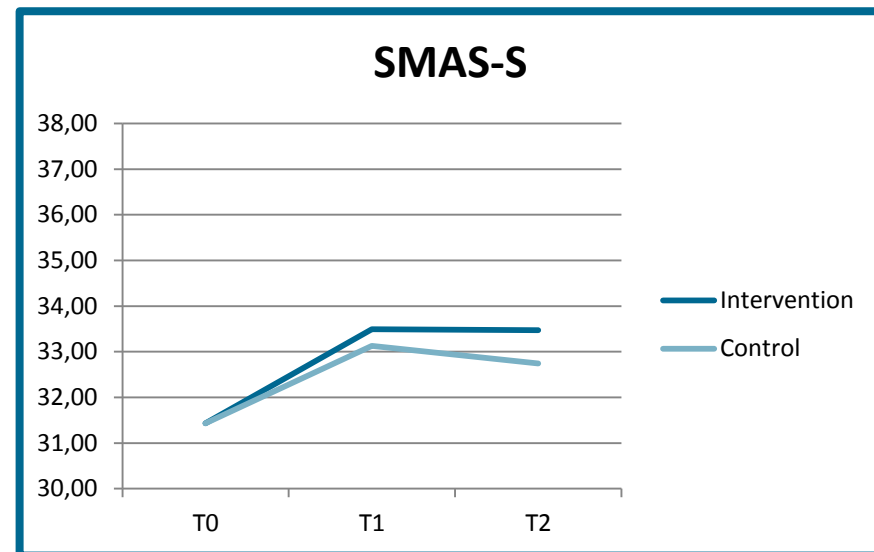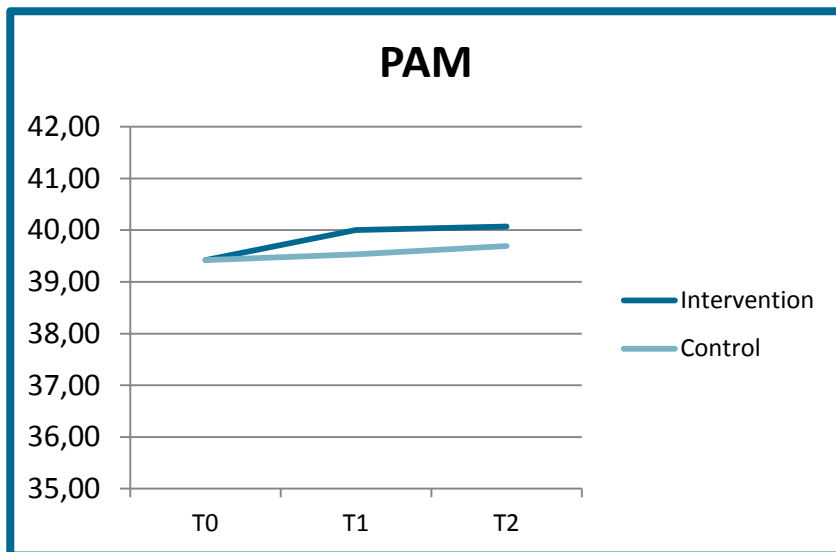

RAND physical functioning
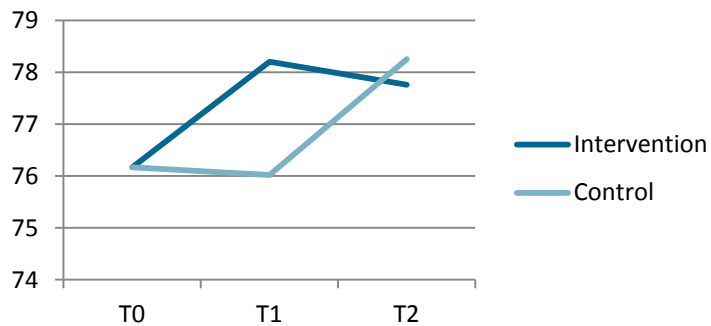
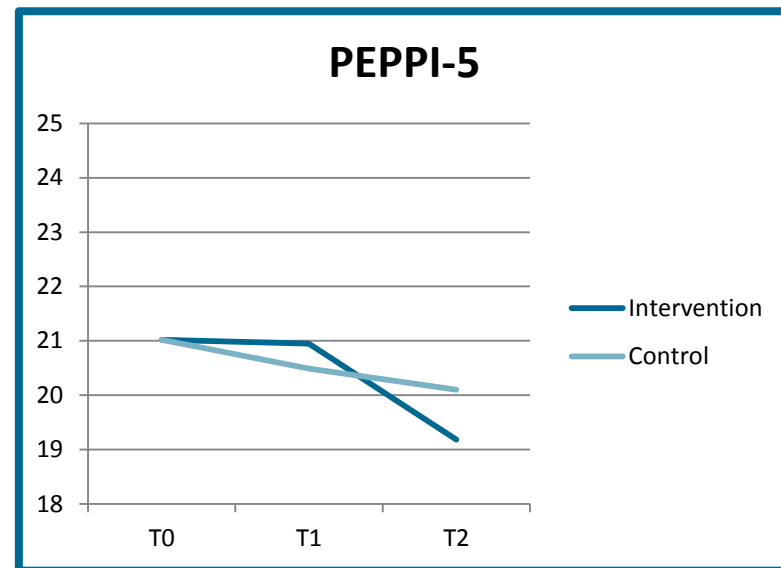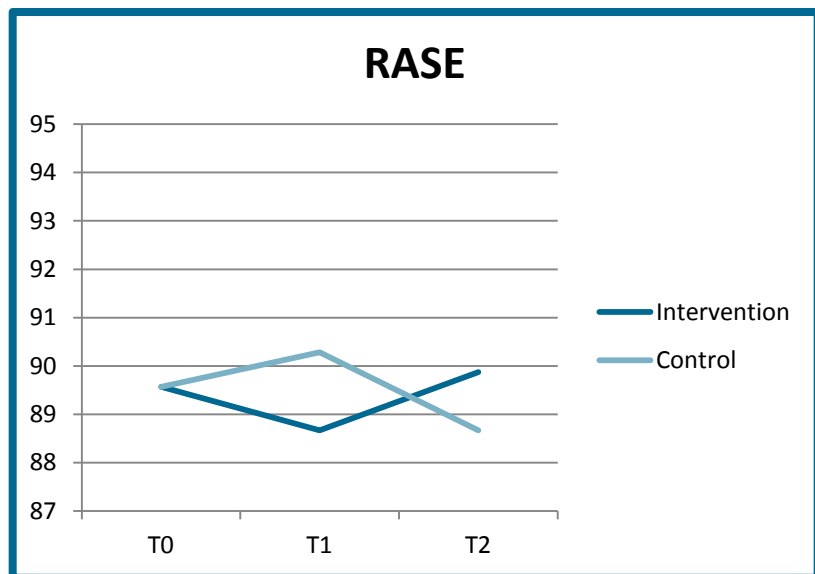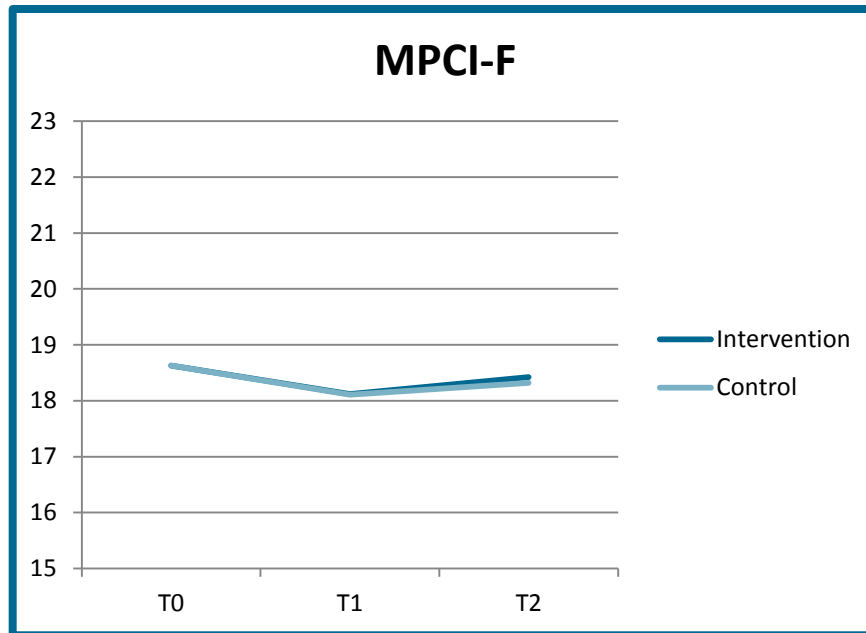RAND social functioning
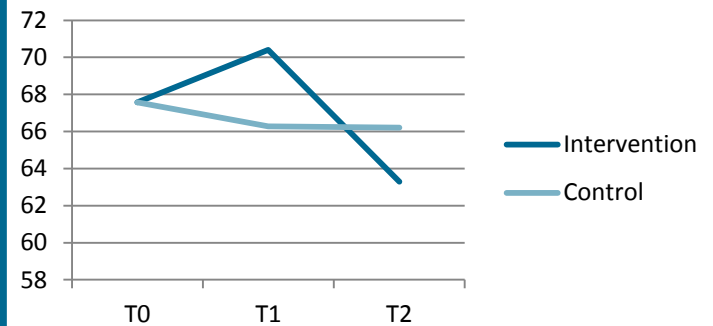
RAND mental health
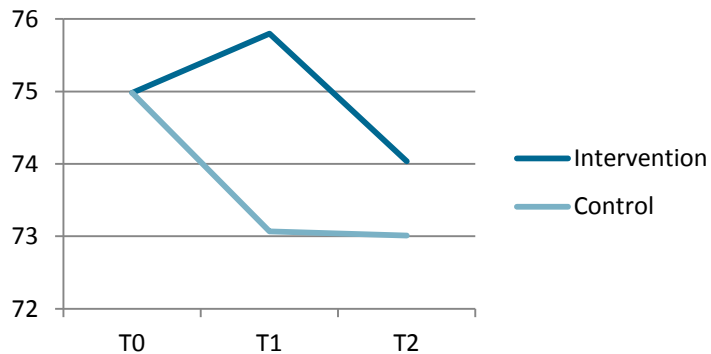
RAND vitality
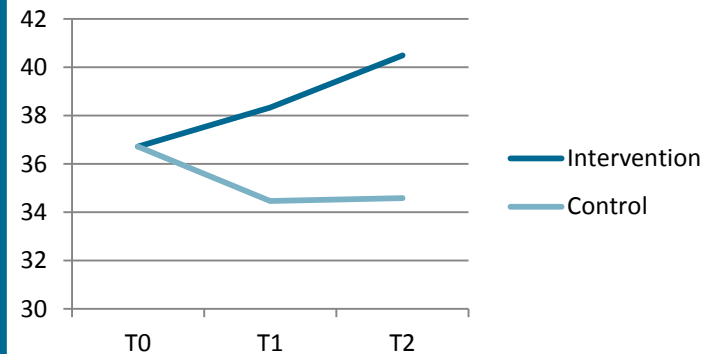
Results – Self-Management
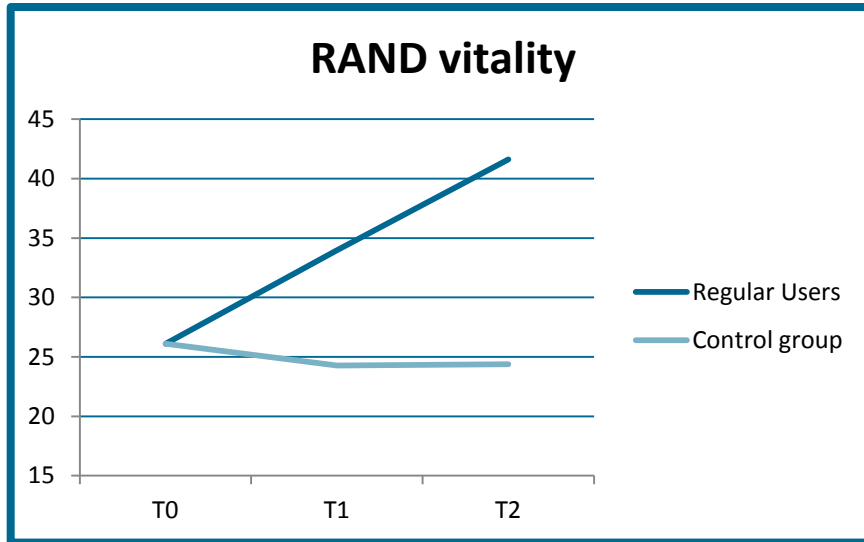
Results – Self Efficacy

Results – Focus on fatigue

Results – users of the e-health programme

- Fidelity: the programme was delivered to 78 patients

  - 55 patients used the programme

  - 23 patients did not use the programme

Results – Analyses per protocol

**RAND vitality**

- Increase of the effect

Results – Process evaluation

- Fidelity: the programme was delivered to 78 patients

  - 55 patients used the programme

  - 23 patients did not use the programme

- Interviewed 4 groups of patients to examine the engagement with the programme

  - Non-users – 4 patients

  - 1-5 logins – 4 patients

  - > 6 logins mainly registration– 7 patients

  - > 6 logins courses– 6 patients

Results – Courses
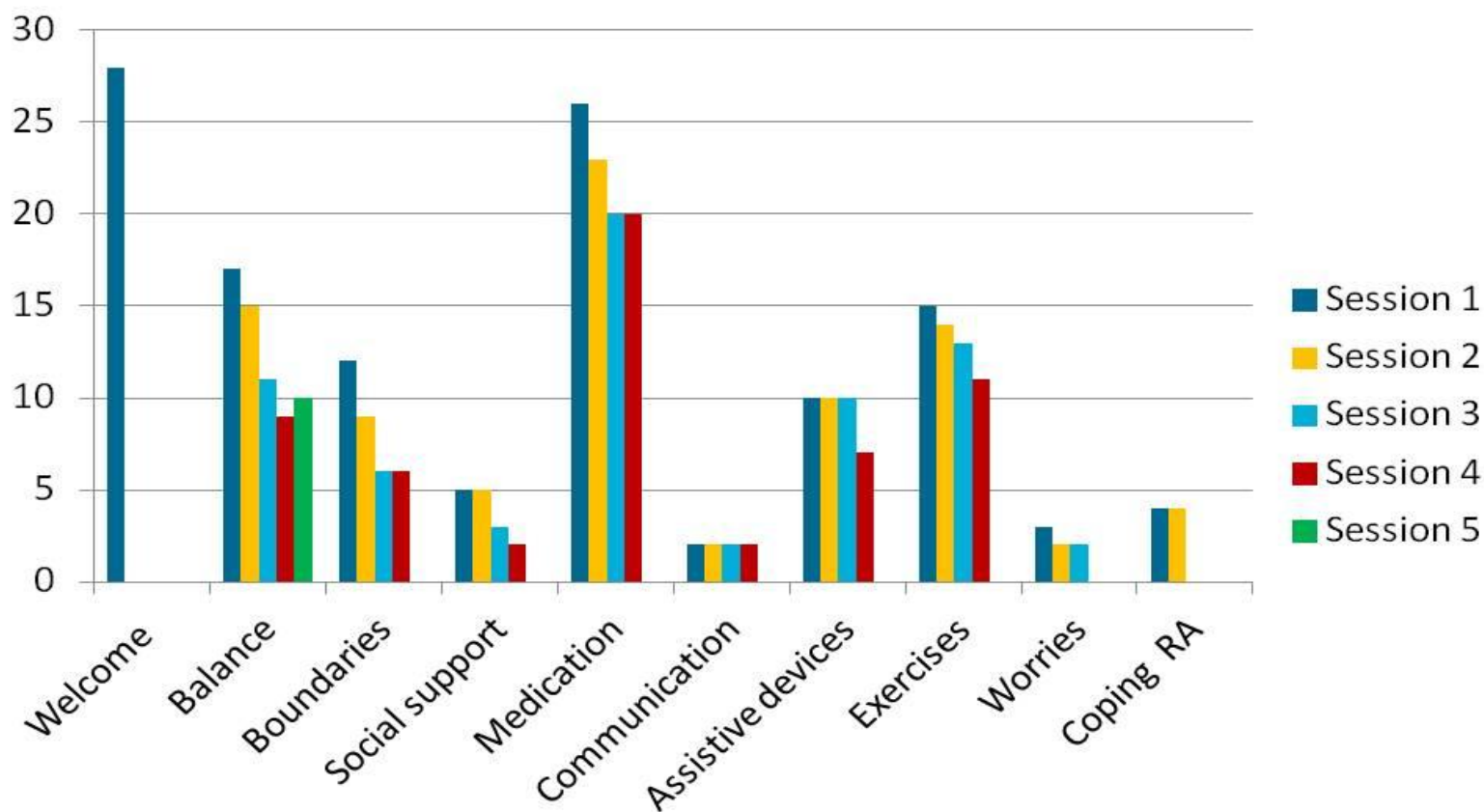
Results – Use online programme 1 year
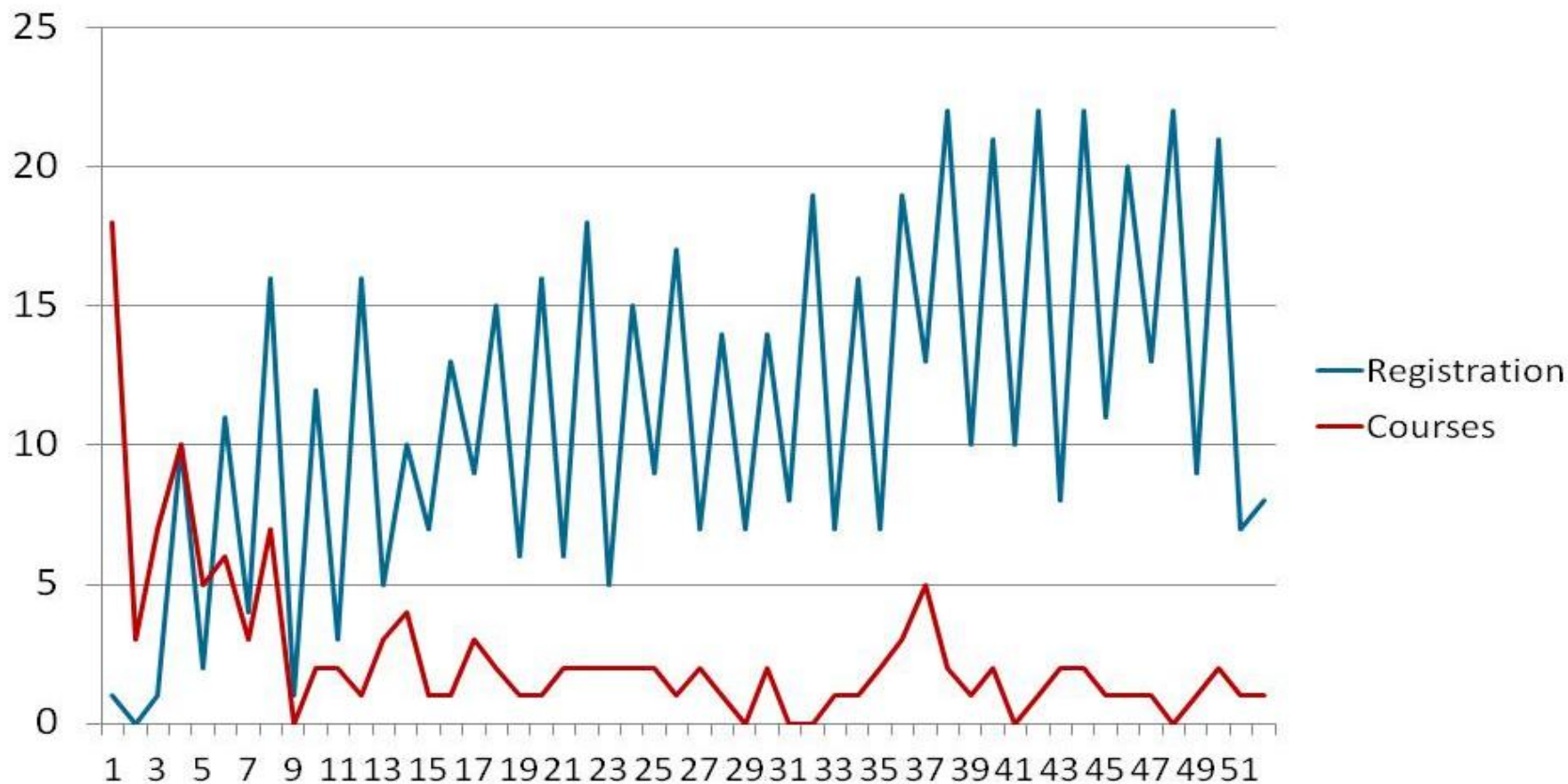
Conclusion

- Choosing the correct outcome is important

- Further analyses are needed to concluded which of the outcomes is appropriate for this online self-management programme

- The online self-management programme was highly used

- The results of the interviews will show more understanding of the non-users of e-health programme

Summary

- Development of the e-health self-management programmes

- The evaluation

  - Pilot RCT

  - Process evaluation