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
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

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

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

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

Evaluation
- Assessing effectiveness
- Understanding change process
- Assessing cost effectiveness

Implementation
- Dissemination
- Surveillance and monitoring
- Long term follow-up

(Craig P et al. 2008)
Self-Made & Sound – 4 patient groups

CVD
VAAT IN ZICHT

SMI
e-IMR

RA
REUMA ZELF TE LUIF

CKD
Mijn Kinderniernet
The development: Intervention Mapping

• A systematic framework for the development and implementation of health promotion programmes

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

• 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
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
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
Self-Made & Sound Project

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

Saskia Puijk-Hekman

6 October 2016
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 symptoms, treatment, physical and psychological consequences and lifestyle changes inherent in living with a chronic condition”.

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

---


### Development Group CVD

<table>
<thead>
<tr>
<th>Patient Development Group</th>
<th>Professional Development Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>- 1 female</td>
<td>- Medical specialist in general and vascular medicine</td>
</tr>
<tr>
<td>- 6 males</td>
<td>- Neurology nurse</td>
</tr>
<tr>
<td></td>
<td>- Cardiology nurse</td>
</tr>
<tr>
<td></td>
<td>- Vascular surgery nurse</td>
</tr>
<tr>
<td></td>
<td>- Psychologist</td>
</tr>
<tr>
<td></td>
<td>- Dietician</td>
</tr>
<tr>
<td></td>
<td>- Physical therapist</td>
</tr>
</tbody>
</table>
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)

<table>
<thead>
<tr>
<th>Problems</th>
<th>Determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical</strong></td>
<td>1. Knowledge</td>
</tr>
<tr>
<td>Obesity, fatigue, pain, sexual dysfunction</td>
<td>2. Awareness</td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td>3. Risk perception</td>
</tr>
<tr>
<td>Fear, stress, depressive feelings</td>
<td>4. Attitude</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td>5. Self-efficacy</td>
</tr>
<tr>
<td>Interacting with professionals, medication non-adherence</td>
<td>6. Subjective norm</td>
</tr>
<tr>
<td><strong>Lifestyle changes</strong></td>
<td>7. Motivation (intention)</td>
</tr>
<tr>
<td>Unhealthy nutrition, physical inactivity</td>
<td>8. Habits</td>
</tr>
<tr>
<td><strong>Daily life</strong></td>
<td></td>
</tr>
<tr>
<td>Setting boundaries, coping with changed role in family, job and society</td>
<td></td>
</tr>
</tbody>
</table>
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\textsuperscript{1}

• Discussion in the development groups

\textsuperscript{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

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)\textsuperscript{1,2}
- Select intervention methods
- Develop practical applications
- Discussion in the development groups

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)?

- Modelling
- Setting graded tasks
- Goal setting

All three strategies can be used

Go to [www.menti.com](http://www.menti.com), enter the code 77 79 81 and vote!
# Practical applications

**Objective:** Patients need to set boundaries

## Practical applications – Setting boundaries

<table>
<thead>
<tr>
<th>e-health program ‘Vascular View’</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Screening, monitoring and tailored feedback</td>
</tr>
<tr>
<td>• General and persuasive information</td>
</tr>
<tr>
<td>• Tailored exercises</td>
</tr>
<tr>
<td>• Peers telling (video) their experiences – what helped them &amp; what where pitfalls</td>
</tr>
<tr>
<td>• Goal-setting</td>
</tr>
</tbody>
</table>
Summary

• Theoretical background of ‘Vascular View’
  
  Step 1 Needs assessment
  
  Step 2 Objectives
  
  Step 3 Theory
Intervention Mapping

- A systematic framework for the development and implementation of health promotion programs\textsuperscript{1,2}

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

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:

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

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1. e-Powered Parents is in collaboration with the Dutch Kidney Foundation
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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.
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 Model¹:

- Singular focus;
- Simple architecture;
- Prominent contents;
- Explicit navigation;
- Inclusive hyperlink.

Avoiding: mandatory fields; scrolling; large texts

e-IMR applications

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

1. Going back to school in 2020
   - In progress

2. Restore relation with my family
   - In progress

Add a new goal
### My short term recovery goals:

<table>
<thead>
<tr>
<th>Short term goal</th>
<th>Attainable steps</th>
<th>Achievement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 restore daily rhythm</td>
<td>1.1 in bed between 10:30 PM and 8:30 AM</td>
<td>Accomplished</td>
</tr>
<tr>
<td>1.2 visiting day-center daily</td>
<td>1.2 visiting day-center on Wednesday during four weeks</td>
<td></td>
</tr>
<tr>
<td>2.1 visiting my sister</td>
<td>2.1 calling my sister</td>
<td>In progress</td>
</tr>
<tr>
<td>2.2 visiting my farther</td>
<td>2.2 meeting her in the park</td>
<td></td>
</tr>
<tr>
<td>2.3 visiting my mother</td>
<td>2.3 the same order</td>
<td></td>
</tr>
</tbody>
</table>
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 afgeloop week had. Dit doet u met een score van 0 tot 5.
Monitoring symptoms

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

In the last week: How much did you suffer from

Depression
- I want an explanation about depression
  This week I suffered quite a lot of depression

Anxiety
- I want an explanation about anxiety
  This week I suffered of anxiety extremely
Monitoring symptoms

Monitored Symptoms:
- Sleeping problems
- Low energy
- Anger
- Concentration problems

Results
Intervention Mapping

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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
  - Newsletters
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 ??
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
Development of a complex intervention

MRC Framework

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

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(Craig P et al. 2008)
Intervention Mapping

- 6 steps
  1. Needs assessment
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  4. Program components
  5. Implementation
  6. Evaluation

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

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>RA</th>
<th>CVR</th>
<th>SMI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General</strong></td>
<td>Patient characteristics</td>
<td>Patient Activation Measure</td>
<td>PAM 13)</td>
</tr>
<tr>
<td></td>
<td>Patient Activation Measure</td>
<td>Quality of Life (Rand 36)</td>
<td></td>
</tr>
<tr>
<td><strong>Specific</strong></td>
<td>SMAS-S</td>
<td>PEPPi-5</td>
<td>BSI</td>
</tr>
<tr>
<td></td>
<td>PEPPi-5</td>
<td>LSQ</td>
<td>IMR-scales</td>
</tr>
<tr>
<td></td>
<td>MPCI-F</td>
<td>CSES</td>
<td>MANSA</td>
</tr>
<tr>
<td></td>
<td>RASE</td>
<td>MMAS-8</td>
<td>MHRM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BMQ</td>
<td></td>
</tr>
<tr>
<td><strong>Process</strong></td>
<td>Actual participation in the intervention &amp; feasibility</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Step 6 Evaluation (2)

- Pilot RCT

Baseline

200 RA-patients
2 hospitals

R

T1
n=100
Online Self-Management programme

T2
n=100

Intervention

Control
## Methods – outcomes RA

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>Rand 36</td>
</tr>
<tr>
<td>Self-management behaviour</td>
<td>PAM-13</td>
</tr>
<tr>
<td></td>
<td>SMAS-S</td>
</tr>
<tr>
<td>Focus on fatigue</td>
<td>MPCI-F</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>RASE</td>
</tr>
<tr>
<td></td>
<td>PEPPPI-5</td>
</tr>
</tbody>
</table>
# Methods – process evaluation

<table>
<thead>
<tr>
<th>Key components</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>The used procedure to approach and attract patients</td>
</tr>
<tr>
<td>Fidelity</td>
<td>% patients to which the program was delivered</td>
</tr>
<tr>
<td>Dose delivered</td>
<td>Delivery of the programme with the courses</td>
</tr>
<tr>
<td>Dose received</td>
<td>The use of the courses in the programme &amp; satisfaction</td>
</tr>
<tr>
<td>Reach</td>
<td>% patients that used the programme</td>
</tr>
<tr>
<td>Context</td>
<td>Influencing factors</td>
</tr>
</tbody>
</table>

1 Steckler & Linnan (2002)
## Methods – data collection & analyses

<table>
<thead>
<tr>
<th></th>
<th>Questionnaire</th>
<th>Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient characteristics</td>
<td>Baseline</td>
<td></td>
</tr>
<tr>
<td>Outcomes</td>
<td>Baseline – 6 – 12 months</td>
<td>12 months</td>
</tr>
<tr>
<td>Satisfaction &amp; experience</td>
<td>6 – 12 months</td>
<td>12 months</td>
</tr>
<tr>
<td>Login data</td>
<td>6 – 12 months</td>
<td></td>
</tr>
</tbody>
</table>

- 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

Follow-up

Analyses

Usual care n=79
T1: n =74
T2: n =73
n=73

Intervention n=78
T1: n =58
T2 n =54
n=54
### Results – who are the participants?

<table>
<thead>
<tr>
<th></th>
<th>Baseline (T0)</th>
<th>Usual Care</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women, n (%)</td>
<td>52 (66%)</td>
<td>51 (65%)</td>
<td></td>
</tr>
<tr>
<td>Age, mean in yrs (SD)</td>
<td>63 (10.22)</td>
<td>61 (11.34)</td>
<td></td>
</tr>
<tr>
<td>RA since, mean in yrs (SD)</td>
<td>17 (11.33)</td>
<td>14 (11.40)</td>
<td></td>
</tr>
<tr>
<td>Educational level n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>28 (35%)</td>
<td>10 (13%)</td>
<td></td>
</tr>
<tr>
<td>Medium</td>
<td>28 (35%)</td>
<td>43 (55%)</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>23 (29%)</td>
<td>25 (32%)</td>
<td></td>
</tr>
</tbody>
</table>
Results – Quality of life

RAND physical functioning

- Intervention
- Control

T0, T1, T2

RAND mental health

- Intervention
- Control

T0, T1, T2

RAND social functioning

- Intervention
- Control

T0, T1, T2

RAND vitality

- Intervention
- Control

T0, T1, T2
Results – Self-Management

**PAM**

- **Intervention**
- **Control**

**SMAS-S**

- **Intervention**
- **Control**
Results – Self Efficacy

**RASE**

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>90</td>
<td>88</td>
<td>92</td>
</tr>
<tr>
<td>Control</td>
<td>89</td>
<td>91</td>
<td>94</td>
</tr>
</tbody>
</table>

**PEPPI-5**

<table>
<thead>
<tr>
<th></th>
<th>T0</th>
<th>T1</th>
<th>T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>25</td>
<td>20</td>
<td>18</td>
</tr>
<tr>
<td>Control</td>
<td>24</td>
<td>21</td>
<td>19</td>
</tr>
</tbody>
</table>
Results – Focus on fatigue

![Graph showing MPCI-F scores over time for Intervention and Control groups]

- **MPCI-F**

  - **T0**
  - **T1**
  - **T2**

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

- 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