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Self-management of long-term conditions

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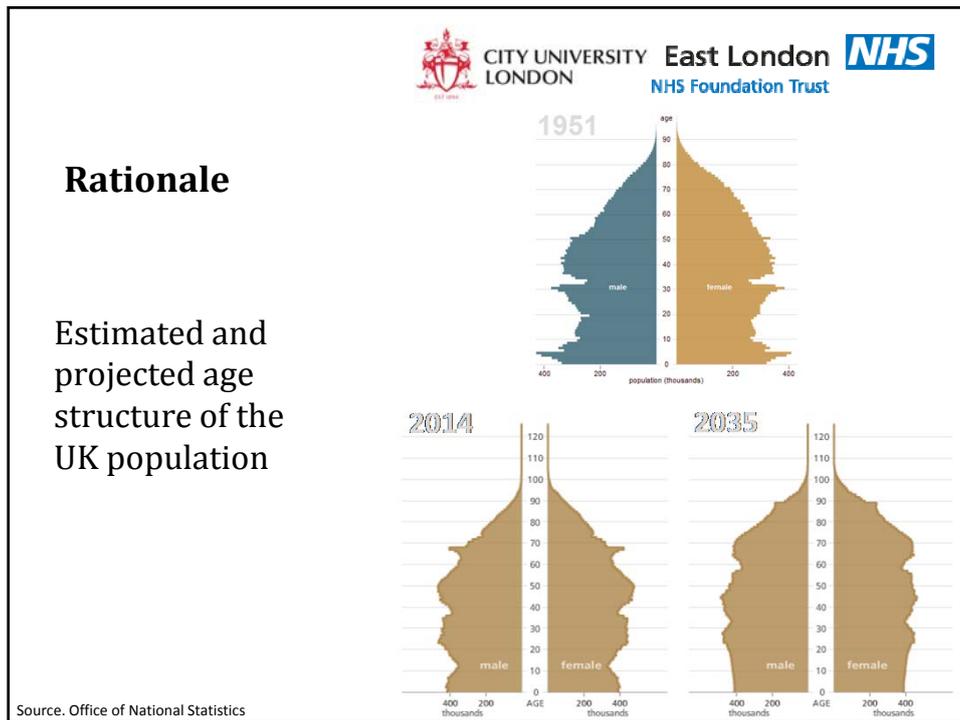


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Aims

- ✓ Rationale for self-management
- ✓ Define self-management
- ✓ What is the evidence?
- ✓ What are the challenges of designing, evaluating and implementing self-management interventions?




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UK Policy

- The NHS Outcomes Framework 2014-15 (Department of Health, 2013)
- Five key domains:

Domain 1	Preventing people from dying prematurely;
Domain 2	Enhancing quality of life for people with long-term conditions;
Domain 3	Helping people to recover from episodes of ill health or following injury;
Domain 4	Ensuring that people have a positive experience of care; and
Domain 5	Treating and caring for people in a safe environment and protecting them from avoidable harm.

Domain 2 Enhancing quality of life for people with long-term conditions;

- Patient empowerment and support for people with a long-term condition, is vital to enabling them to manage their illness and treatment without needing to go into hospital
- Key indicators one of which is:
 - Proportion of people feeling supported to manage their condition
- Measured based on responses to a question from the GP Patient Survey

Definition

*“...individual’s ability to manage the **clinical** and **psychosocial** consequences, along with the **lifestyle** changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the **cognitive**, **behavioural** and **emotional** responses necessary to maintain a satisfactory quality of life.”*

(Barlow et al., 2002)

Definition

- “...aims at helping patients to maintain a wellness in their foreground perspective” (Lorig *et al* 2003)
- Achieved via 3 sets of tasks (Corbin & Strauss, 1988)
 - **Medical** management
 - Maintaining, changing and creating new meaningful **behaviours** or life roles
 - **Emotional** sequeli

Core self-management skills

Lorig and Holman (2003)

- Problem solving
- Decision making
- Resource utilisation
- Forming of a patient/health care provider partnership
- Taking action



Evidence

- HED-SMART
- A self-monitoring and patient-initiated follow-up service for patients with rheumatoid or psoriatic arthritis
- Systematic reviews and meta-analysis



Multi-behaviours: HED-SMART

Griva et al. *BMC Nephrology* 2011, 12:4
<http://www.biomedcentral.com/1471-2369/12/4>



STUDY PROTOCOL

Open Access

The NKF-NUS hemodialysis trial protocol - a randomized controlled trial to determine the effectiveness of a self management intervention for hemodialysis patients

Konstadina Griva^{1,3*}, Nandakumar Mooppil², Penny Seet², Deby Sarojyay Pala Krishnan², Hayley James^{3,4}, Stanton P Newman^{3,4}

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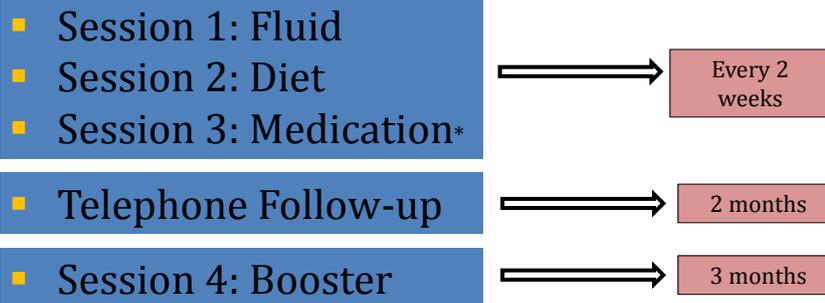


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HED-SMART content



*If no issues with meds – on exercise



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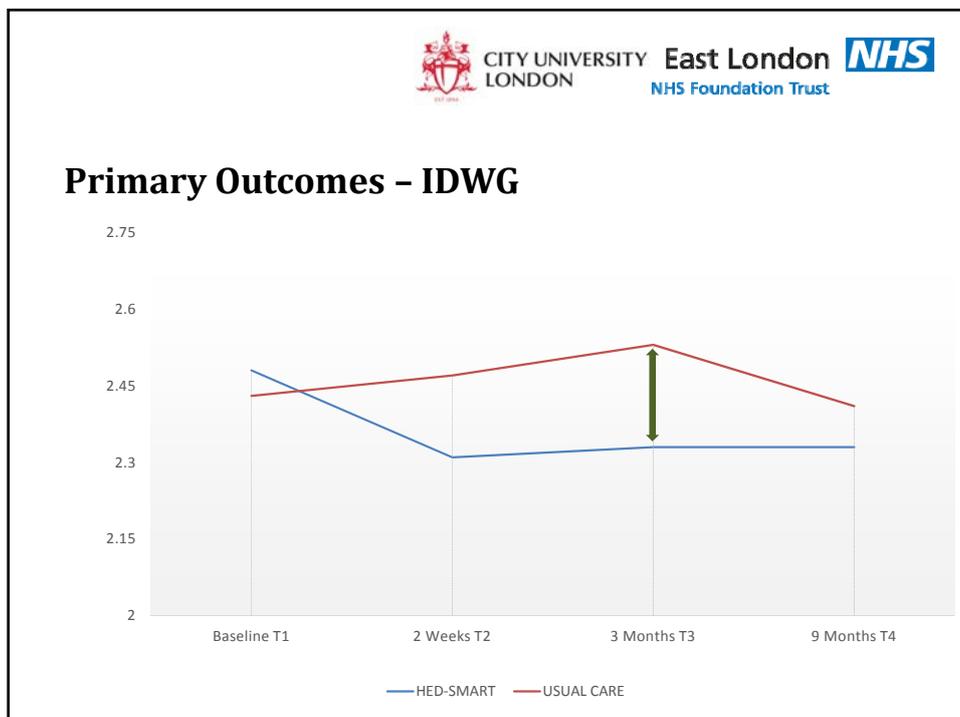
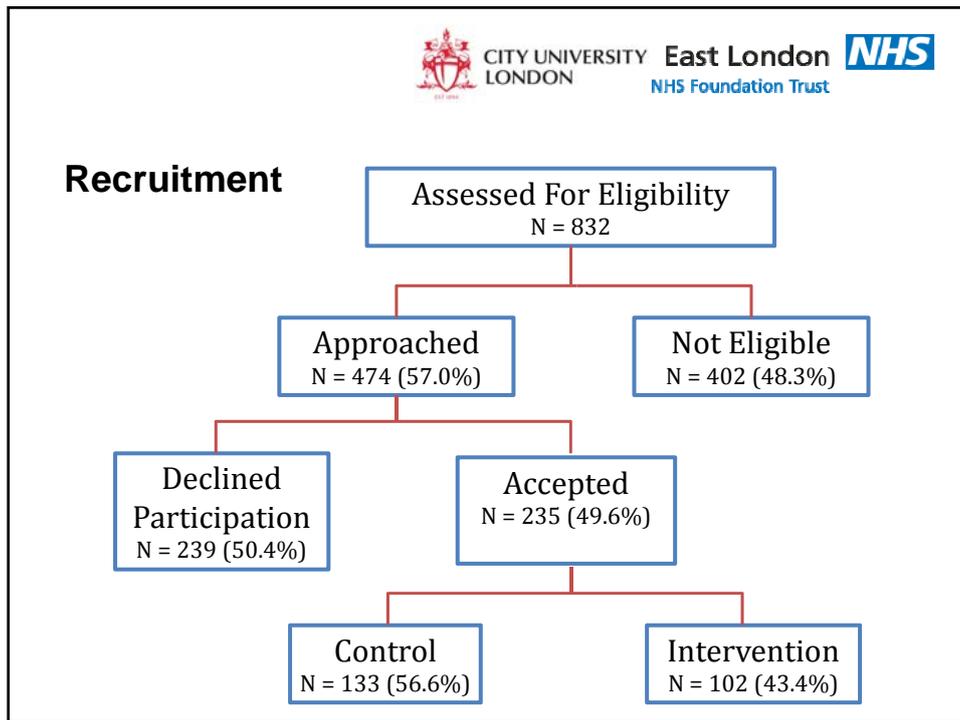
Measures

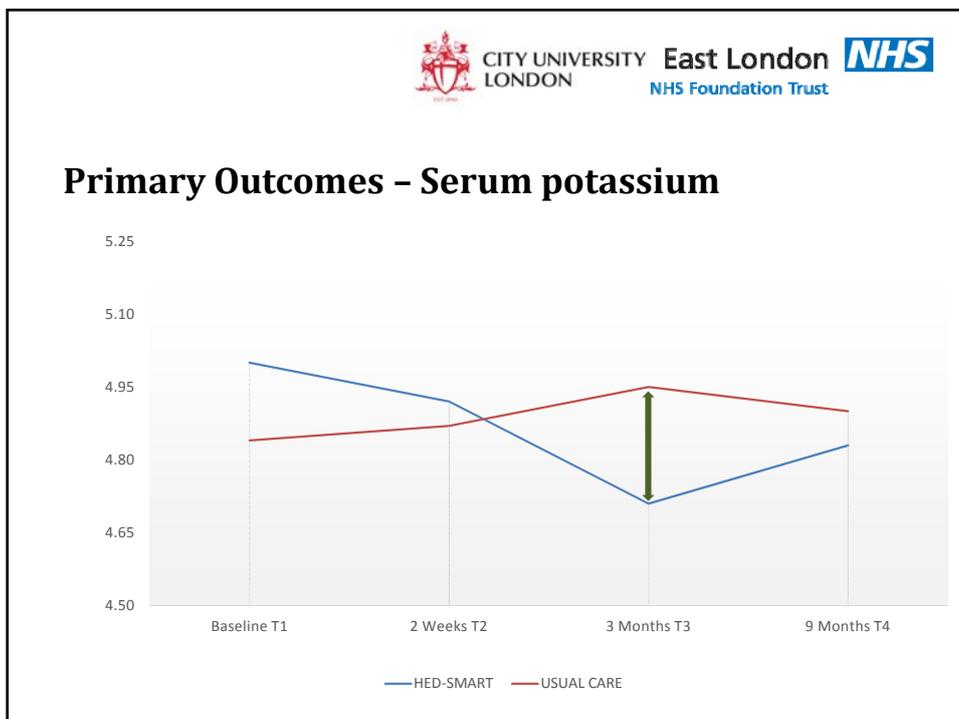
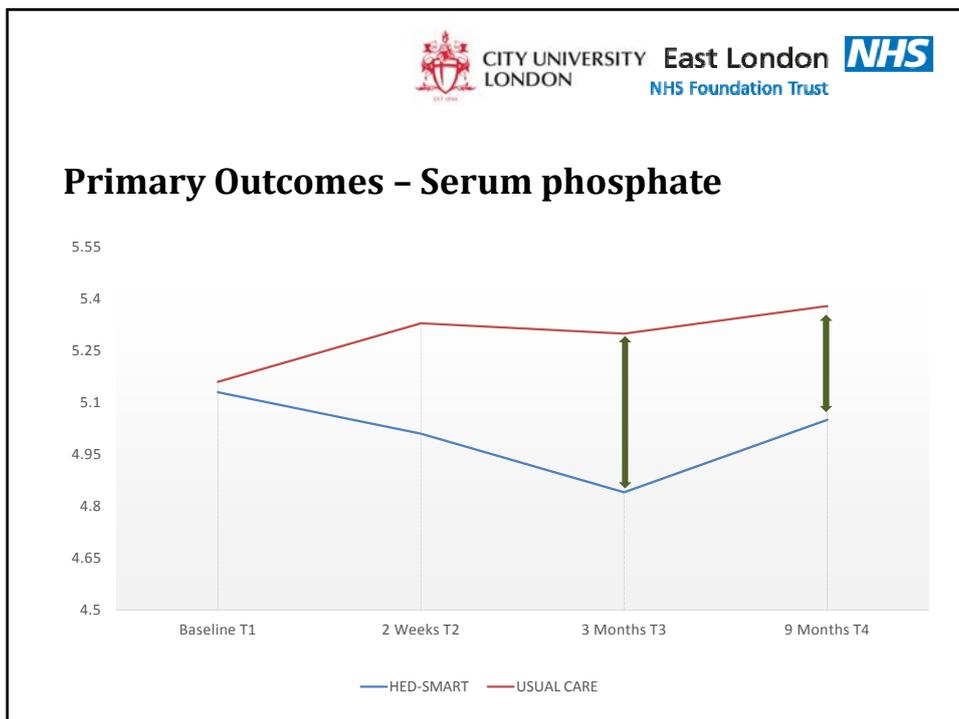
Primary outcomes

- IDWGs, biochemical markers (PO₄; K)

Secondary Outcomes

- Self-report adherence
- Self-management skills
- Quality of Life
- Mood
- Beliefs about medicines
- Self-efficacy



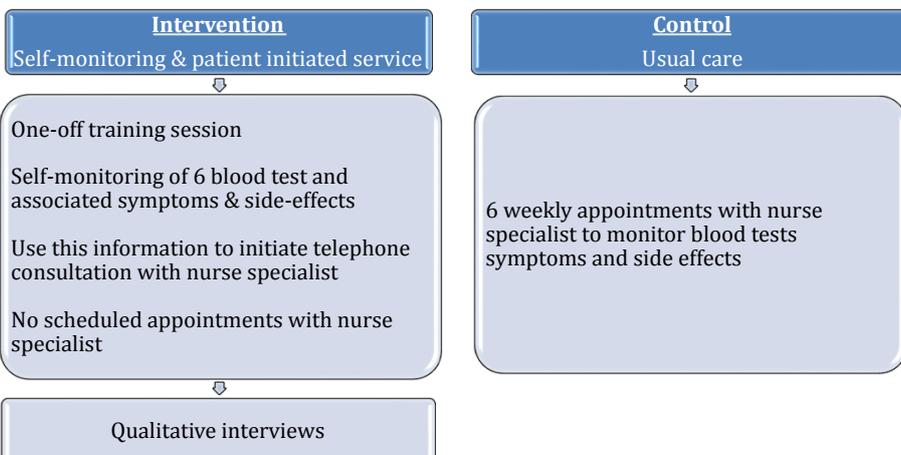


A self-monitoring and patient-initiated follow-up service for patients with rheumatoid or psoriatic arthritis: a randomized controlled trial

McBain, H., Shipley, M. & Newman, S.



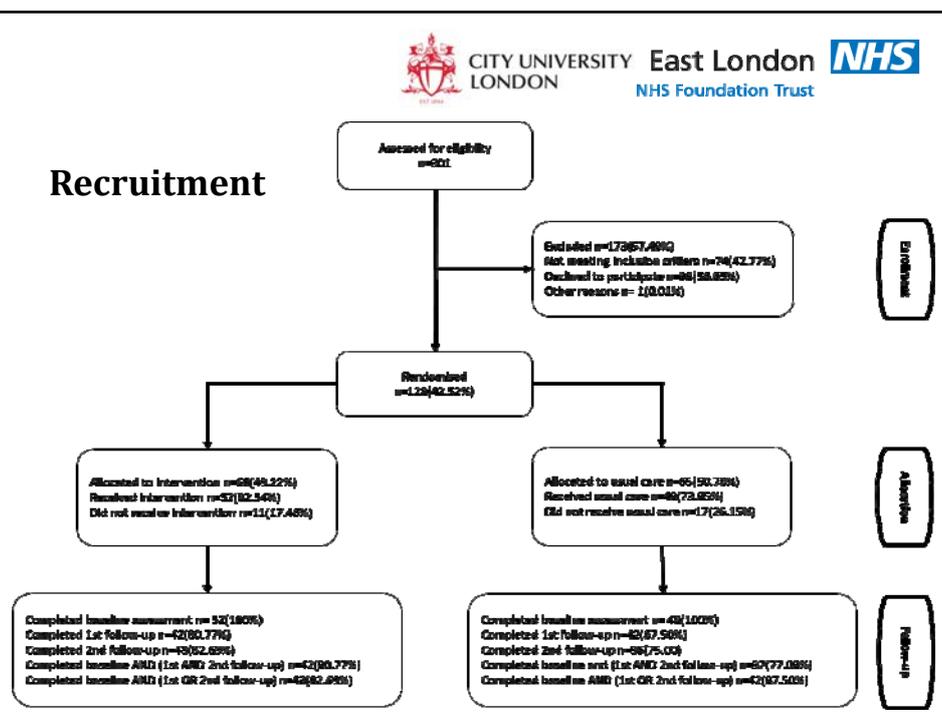
Methods - RCT

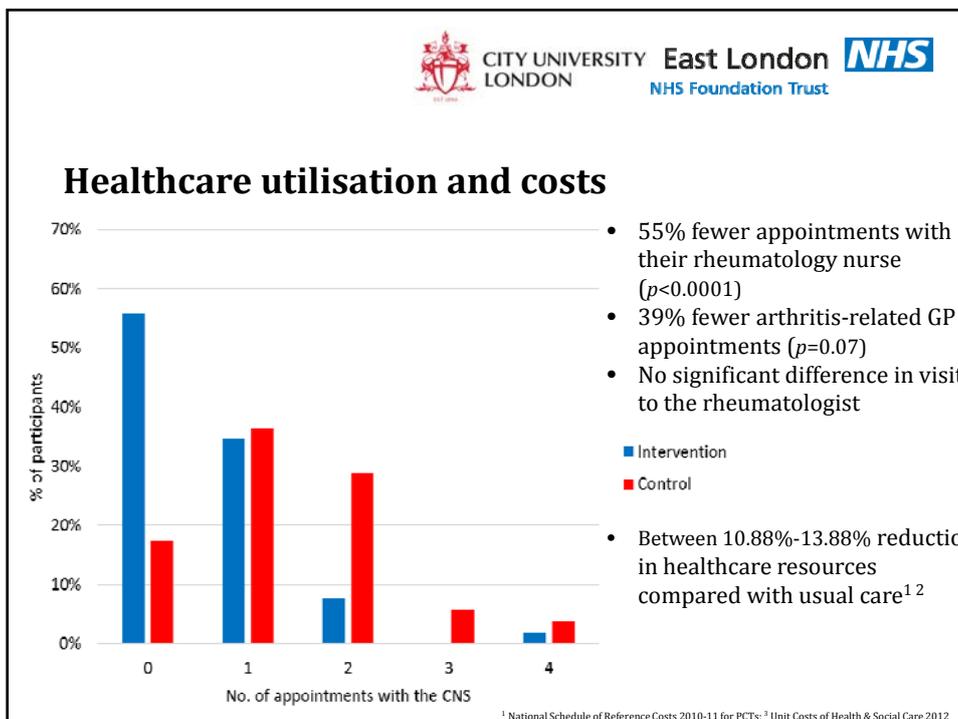
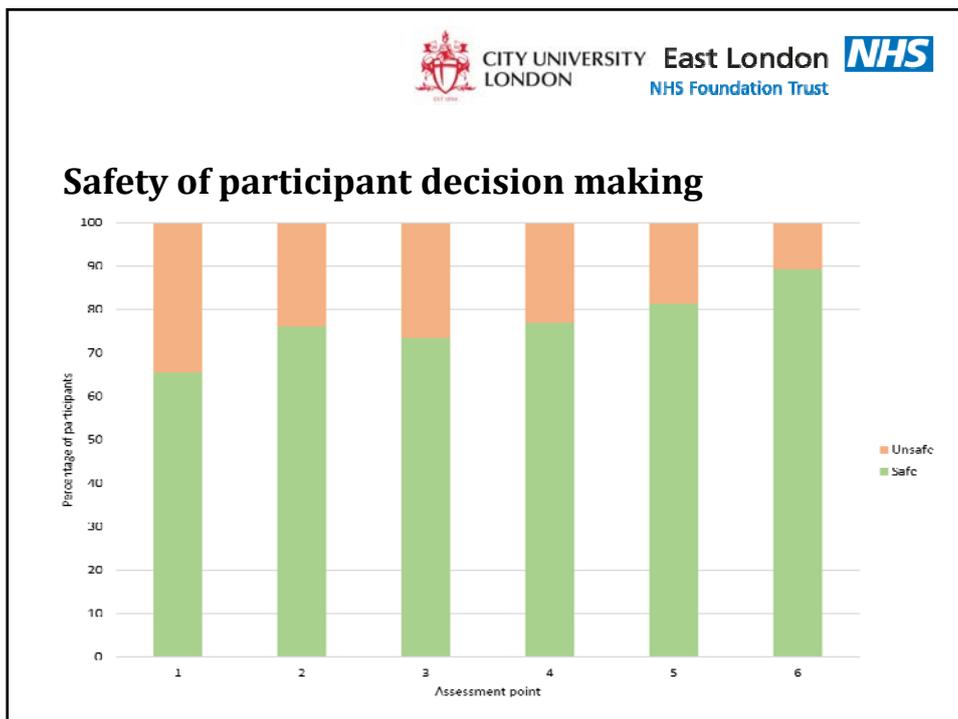


Measures

- Healthcare utilisation
 - Rheumatology nurse & consultant visits - EPR
 - Arthritis-related GP visits – self-reported
- Healthcare costs
- Psychological outcomes
 - Quality of life – SF-12®
 - Mood - HADS
- Psychosocial process variables
 - Self-efficacy – GSES, HeiQ™, MeiQ™
 - Knowledge – MiRAK, MiPsAK
 - Treatment burden – 1 item
 - Illness & treatment beliefs – IPQ-R, BMQ

Recruitment







Secondary outcomes

- No significant differences between groups on treatment response, pain, fatigue, quality of life or disability
- No significant difference between groups on self-efficacy, mood, illness and treatment beliefs, treatment burden or knowledge
- No significant mediators of intervention effectiveness



Qualitative results

Theme 1 – Burden of care

- Sub-theme: Efficiency
- Sub-theme: Impact on work life
- Sub-theme: Normality

Theme 2 – The self-management process

- Sub-theme: Knowledge
- Sub-theme: Control
- Sub-theme: Behavioural regulation

Theme 3 – Conflict

- Sub-theme: Between laboratory tests and symptoms
- Sub-theme: Between study guidelines and practice

Theme 4 – Anxiety

Theme 5 – A tailored service

- Sub-theme: Right time
- Sub-theme: Right method

Theme 1 – Burden of care

- Sub-theme: Efficiency

“No, I think that was one of the reasons why I found it quite irritating was that when I came to see the rheumatologist you know I waited for like two hours sometimes and got seen for two minutes, seeing the nurse was better it was pretty quick, but still generally things were ok so I just got sent away again it seemed abit tedious to wait all that time to be told everything was fine come back in a couple of month.” – JD
- Sub-theme: Impact on work

“You know, and I’ve spend 45 minutes in the waiting room and you know, it comes at a time cost, particularly when your paid by the hour it can come at a much larger cost” AS

Theme 2 – The self-management process

- *“But yes I was probably more knowledgably and I was able to ask him more relevant questions.” EK.*
- *“...it’s just more control of my own time.....it allows me to control the monitoring to suit my requirements rather than the hospital schedule” – NP*
- *“...seeing my results has enabled me to understand my body and its reactions to the disease and to methotrexate.” – RG*



Theme 5 - A tailored service

- Subtheme 1 – Right Time
 - *“Because the things were so snap shoty, it’s impossible for people, for three months you could be really ill but the whole care is based on how you were there and then. That’s frustrating.” – DW*
 - *“Yeah I mean as long as my results were within the ranges specified, I was quite happy not to see anybody”. – AP*

- Subtheme 2 – Right Method
 - *“I knew that if I had a problem that if I felt unwell, really unwell then I would phone [the nurse] anyways and I knew I could always speak to her. So I did not feel I was just put in the study and shipped out and left on my own to deal with it I felt there was support there in place for me if I needed it.” – JH*



Systematic reviews

Self-management interventions for adults with type 2 diabetes mellitus (Review)

Pal K, Eastwood SV, Michie S, Farmer AJ, Barnard MI, Peacock R, Wood B, Isaacs JD, Murray E

RESEARCH A
Self-man:
health ca
outcome
Maria Panagioti*, C
Stanton Newman

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CHALLENGE 1: HETEROGENEITY

Heterogeneity

- Content (active ingredients)
- Context
- Mode of delivery
- Method of delivery
- Targeted behaviours
- Outcomes
- Facilitator (who, training)
- Intensity (duration, frequency)
- Theoretical underpinnings

CHALLENGE 2: ACTIVE INGREDIENTS

Challenges - content and terminology

- The techniques used often inadequately described
- Making it difficult to replicate or adapt interventions or to identify which techniques are most effective in changing behaviour and improving outcomes
- Understanding content is vital to understanding mechanisms of action and fidelity



Specifying the active ingredients of diabetes self-management interventions: an analysis using the Behaviour Change Techniques Taxonomy (BCTTv1)

ann. behav. med.
DOI 10.1007/s12160-013-9486-6

ORIGINAL ARTICLE

The Behavior Change Technique Taxonomy (v1) of 93 Hierarchically Clustered Techniques: Building an International Consensus for the Reporting of Behavior Change Interventions

Susan Michie, DPhil, CPsychol · Michelle Richardson, PhD · Marie Johnston, PhD, CPsychol · Charles Abraham, DPhil, CPsychol · Jill Francis, PhD, CPsychol · Wendy Hardeman, PhD · Martin P. Eccles, MD · James Cane, PhD · Caroline E. Wood, PhD



Diabetes self-management & BCTT

- Using the materials of the three most well-established diabetes self-management interventions, the objectives of this study are:
 - I. To describe each programme in terms of the BCTs they intend to implement and the frequency ('dose') with which each BCT is implemented within each programme.
 - II. To compare these intervention components across the three programmes in order to identify the most common and frequently used BCTs and how they are applied across different target behaviours.
 - III. To examine how well the BCTTv1 can be used to describe diabetes self-management interventions and identify any additional BCTs which may need to be added to the BCTTv1 in order to better describe the content of chronic disease self-management interventions more generally.
- By meeting these objectives this study will provide a foundation for designing more effective, evidence-based interventions as it will provide an understanding of the change process that is taking place within these interventions.



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CHALLENGE 3: FIDELITY



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Challenges - Fidelity

- A key element of the quality of implementation is its fidelity, or the degree to which the intervention is delivered as intended
- (a) The absence of a significant effect may lead to a false attribution of the lack of an intervention's effectiveness, but a lack of effect could be due to poor implementation = "type III error"
- (b) Information about fidelity can help one understand why an intervention succeeded or failed.
- (c) Assessing fidelity can help to identify which components have been adapted to meet the specific needs of the health system and its patients, and how these adaptations influenced the outcomes.
- (d) Information on fidelity can help to assess the future feasibility of implementing the intervention



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- 15 primary studies and 5 reviews
- few empirical studies of DSM education programs addressed the issue of fidelity, and when it is, the information provided is often incomplete
- information about the conceptualization and measurement of fidelity is often lacking
- To measure fidelity of DSM programs researchers resort to observation as well as self-report measures by either providers or participants, or both.
- Only one assessed the impact of fidelity on the outcomes of the programme (Griffin et al 2010)





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CHALLENGE 4: LONG-TERM EFFECTS



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Challenges: long-term effects

- Effects in systematic reviews primarily in the short-term
- Cost and resource implications
- Possible solutions:
 - A more fundamental change in how medicine is taught
 - Booster sessions
 - Understanding fidelity

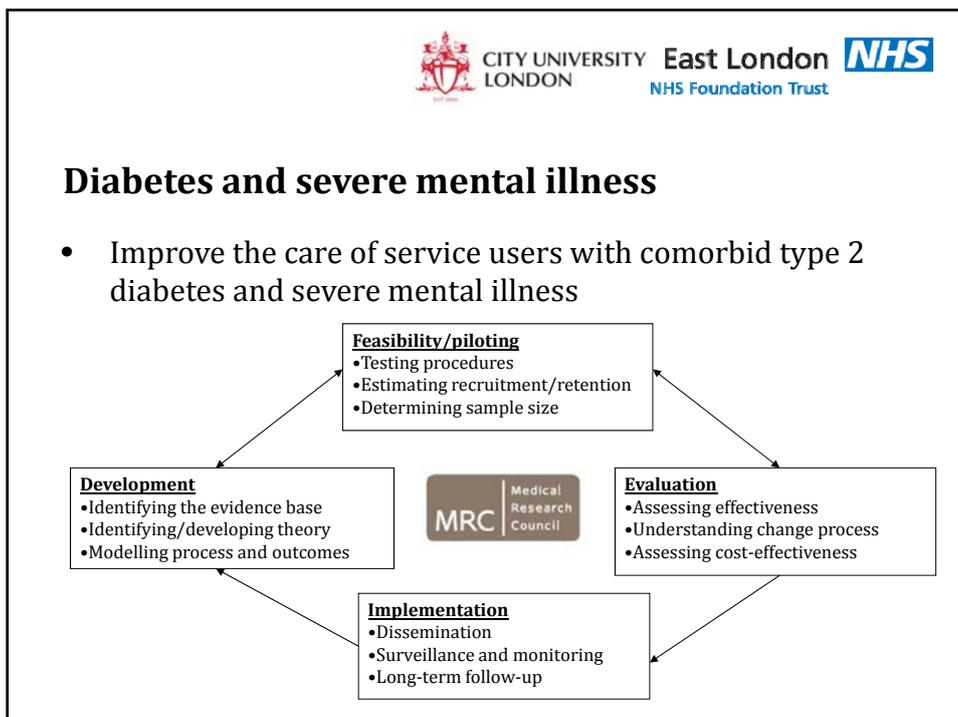
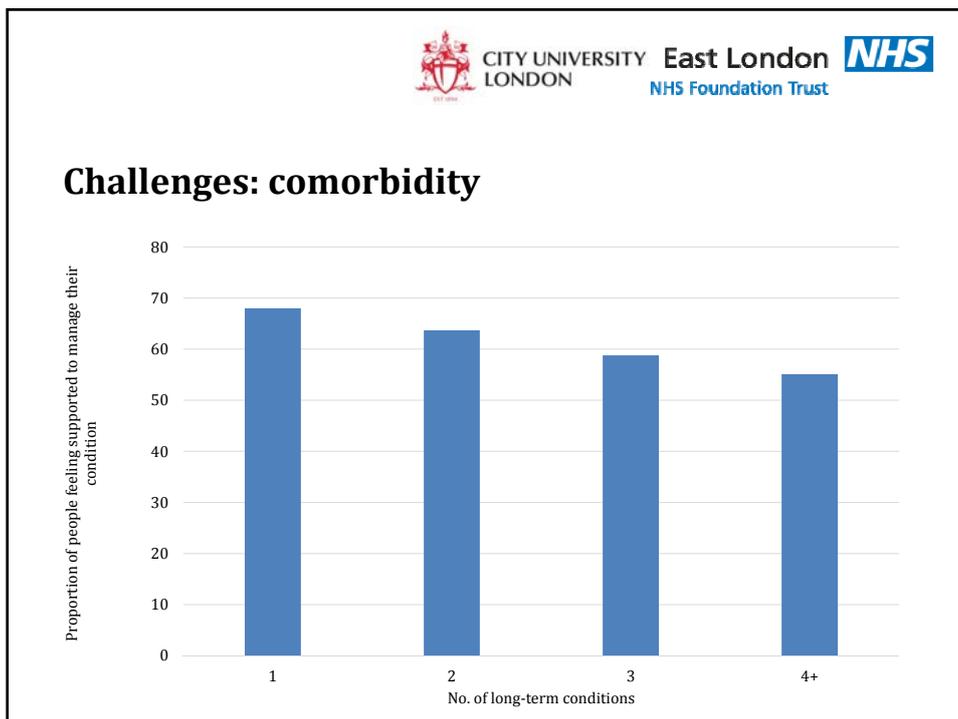


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CHALLENGE 4: COMORBIDITY





Development (ongoing work)

- Identifying the evidence base
 - Cochrane of self-management interventions for people with type 2 diabetes and severe mental illness.
 - Systematic review of healthy lifestyle interventions for people with severe mental illness.
 - Use of technology in the care of physical health for people with severe mental illness.
 - Audit of current diabetes care in ELFT for people with severe mental illness.
- Identifying/developing theory
 - Cochrane of self-management interventions for people with type 2 diabetes and severe mental illness.
 - Diabetes self-management in people with severe mental illness: a qualitative study with service users.
 - Delivery of diabetes care in people with severe mental illness: a qualitative study with healthcare professionals
- Modelling process and outcomes
 - Predictors of delivery of care according to the diabetes standard in people with severe mental illness: the healthcare professionals perspective.
 - Predictors of diabetes self-care in people with severe mental illness.



Conclusion

- Self-management interventions have been found lead to short-term effects on a range of clinical, psychosocial and behavioural outcomes
- Unanswered questions:
 - How do we maintain these effects?
 - Can we better describe the content of interventions?
 - Can we identify the techniques which have the greatest impact on outcomes?
 - Can you identify who will benefit most?

Thank you

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Dean's Lecture Series, School
of Health Sciences

**Understanding patients'
experience of Chronic
Kidney Disease to develop
effective support
programmes**

Professor Konstadina Griva



29th October 2014
Drysdale Lecture Theatre
6-7pm