

# Young people with long term conditions: the role of digital clinical communication in improving health care engagement and health outcome: the LYNC study



## Update and Preliminary Findings

### The Team

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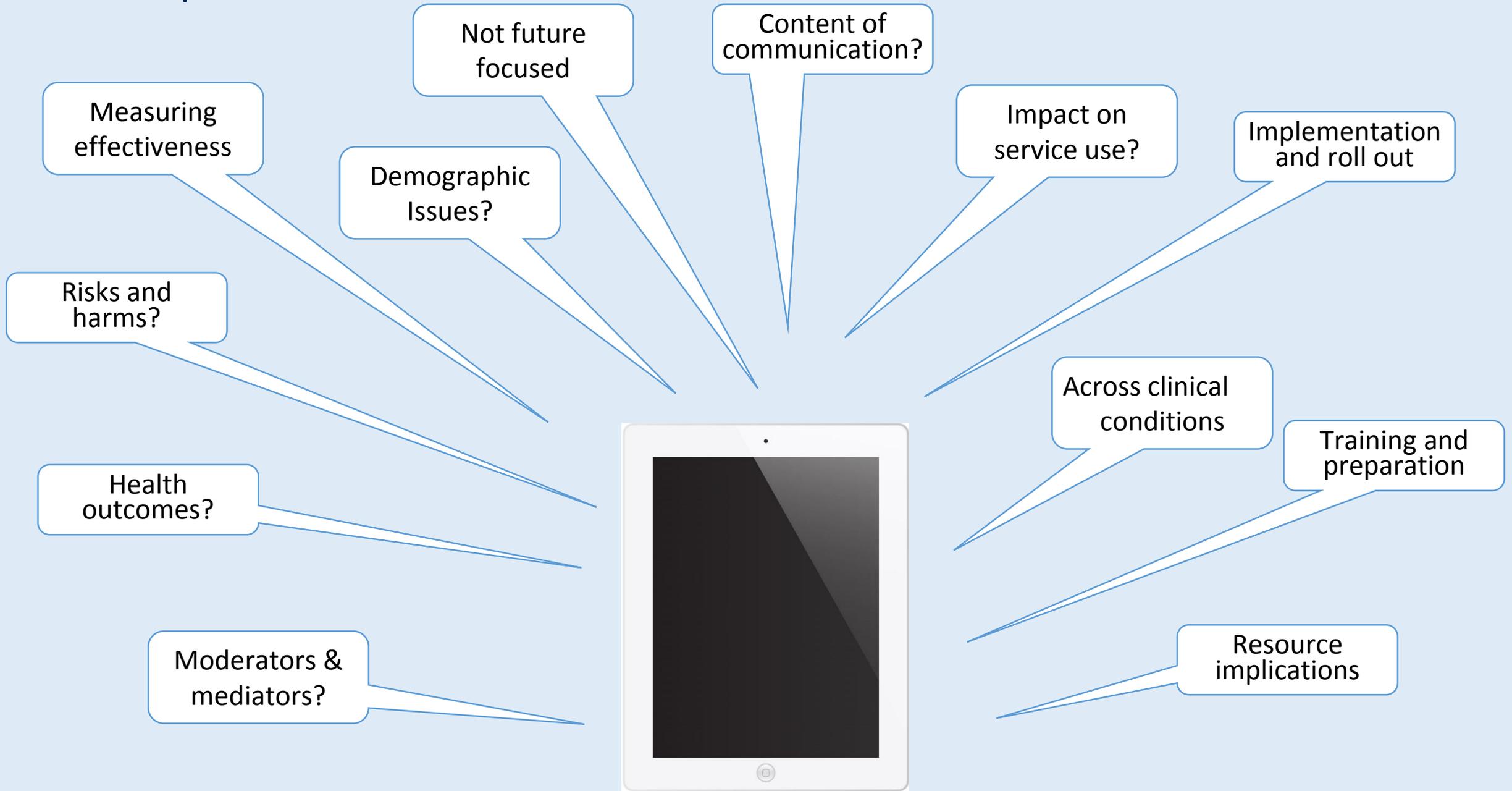
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## Rationale

- Young people with long term conditions disengage with services leading to poorer health outcomes
- Young people are asking to communicate with their clinical team digitally
- Clinicians are using digital communication with young patients
- This communication approach is often out with local NHS Information Governance policy

## Evidence Gaps



## **Research aims**

- To evaluate the impacts and outcomes of digital clinical communications for young people living with a long term condition
- To provide a critical analysis of the use, monitoring and evaluation, of digital clinical communications by NHS providers.

## **Research question**

- What are the effects, impacts, costs and necessary safeguards for digital clinical communications for young people living with long term conditions and engaging with NHS providers?

# 20 case studies

- Clinics supporting 16-24yr olds with a long term condition
- Conditions which are most expensive to the NHS
- Interviews with 15 patients, 5 parents/NOK and 15 clinicians (incl Information Governance Manager & Cauldicott Guardian) and clinician observation
- Clinic and Trust Information Governance Policies
- Annual aggregated clinic data for DNA, A&E and admission rates plus clinical outcome of clinic choice
- Alongside these we have both rapid evidence synthesis and a PPI work streams

# Digital Clinical Communication definitions

## Parameters of DCC definition

- Clinician and/or young person is (or could be) mobile when sending/receiving the communication
- Two-way
- Synchronous or asynchronous
- For clinical care purposes

## Example of DCCs

- Email
- Text
- Mobile phone
- Web portals
- SKYPE/FaceTime
- Social Media (e.g. Facebook/Twitter)

## Research questions for these cases

- What works (or not) for patients, clinicians and NHS Trusts?
- What are the resource implications of DCC for patients and clinicians?
- What are the patient safety issues?
- What are the ethical issues?
- How may DCC have impacted on trust level and clinical outcomes?
- How can the effectiveness of DCC be measured across health conditions?

### Recruited clinical cases by:

- UK location
- Condition
- Age range

### Presenting data today from:

- Diabetes
- Dermatology
- Liver clinics

### Presenting data today on

- What works
- Ethics
- Outcomes
- Health economics
- PPI activity on measuring DCC effectiveness

Midlands	Mental health	Children and adolescents (< 18 years)
Midlands	Mental health	≥16 years
South/South East	Mental health	Children and adolescents < 18 years
East	Mental Health	14-25 years
Midlands	Mental health	A number of clinics inc. for adolescents/young adults
Midlands	Diabetes	11- 18/19 years
South/South East	Diabetes	Transition/adolescent & young adult patients
South/South East	Cancer	Paediatric including young adults (<18 years)
North/North East	Cancer	13-24 years
South/South East	IBD	All ages
South/South East	IBD	Adolescent/young adult clinic (13-24 years)
North/North East	Cystic Fibrosis	≥16 years (~80% population 16-24 years)
Wales	Cystic fibrosis	≥16 years (Adult service but most are under 30)
Midlands	Renal	Young adult (16-21/22 years)
North/North East	Rheumatology	Transition/adolescent & young adult patients
South/South East	Haemoglobinopathy	All ages (inc transition clinic)
South/South East	Liver	Transition/adolescent & young adult patients
South/South East	Dermatology	All ages
North West	Gynaecology	Transition clinic mostly 16-17yrs
Midlands	Various	14-19 years in community

# What works, for whom, where, when and why?

What works for young people....

- Easier for patients and clinicians to keep in touch with each other
- Option of text communication when other things got in the way of a phone conversation
- Advantage of being accessible after the event
- Trusted person who they knew .....and trust was earned

# What works, for whom, where, when and why?

What works for health professionals....

- Workload
- Confidentiality

# Ethical analysis - Young people

- What concerns do patients and clinicians have about confidentiality?
- How does DCC affect the patient/clinician relationship and the clinician's duty of care?
- What regulatory framework is needed to reassure patients and clinicians regarding its use?

- Confidentiality
- Increasing Autonomy
- Better relationships

# Ethical analysis - Health professionals

- What concerns do patients and clinicians have about confidentiality?
- How does DCC affect the patient/clinician relationship and the clinician's duty of care?
- What regulatory framework is needed to reassure patients and clinicians regarding its use?

- Managing patient privacy
- Managing professional boundaries
- Increasing Autonomy

# Reported resource use impact of DCC in a diabetes clinic

## Direct burden of DCC on staff

- Varies considerably: some staff report spending up to 14 hours per week using DCC
- This can be instead of, rather than in addition to, non-DCC activity (e.g. mobile calls replacing landline calls)

## What would happen without DCC in a diabetes clinic?

- 1) Patients would have to come to the clinic with their blood sugar readings
- 2) Patients need to book appointments, which would add ***extra pressure*** to the clinic
- 3) Professionals would struggle with their ***time management***

## Crude estimate of cost savings?

*“On average 2-3 appointments per patient over a period of 3 months”* (Consultant, diabetes clinic)

# DCC – feedback on perceived pathways to patient health benefit and cost savings

## Clinic staff report that DCC:

- Provides information and support in between appointments
- Increases participation by patients in disease management
- Reduces disengagement with therapy regime
- Improves attendance through reminders
- Increases patient confidence in their ability to manage their disease

Therefore DCC has sizeable potential impact on clinic efficiency, long-term disease control and health outcomes.

## ***But***

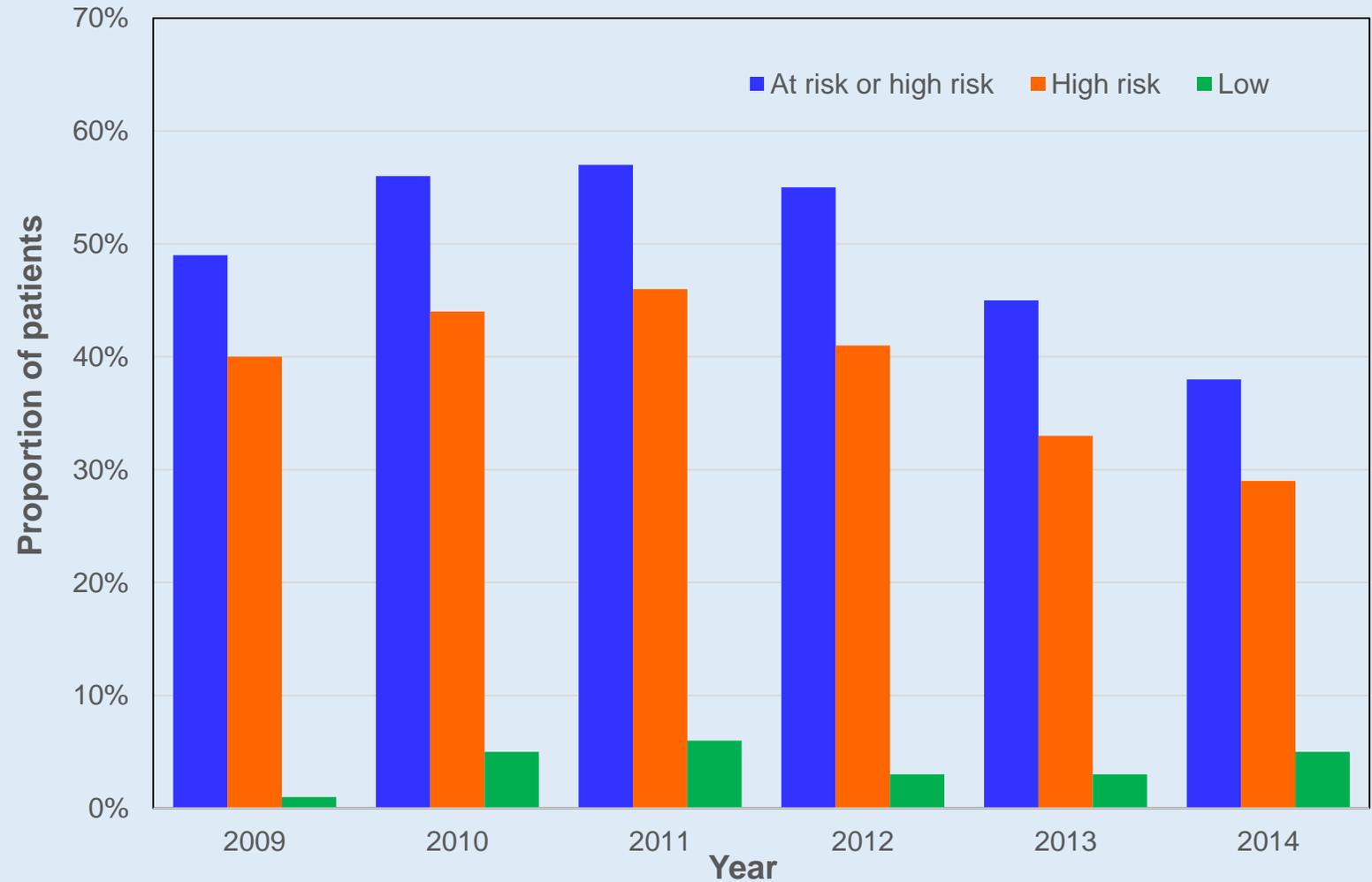
- *it is not a replacement for face-to-face consultation*
- *Quantifying the specific benefits of DCC very challenging*
- *Written DCC (e.g. email /text) improves clarity and avoids miscommunication compared to oral DCC (mobile phone/Skype)*

# Profile of HBA1C levels at diabetes clinic

High risk  
> 80mmol/mol

At risk  
75-80mmol/mol

Low  
< 50mmol/mol



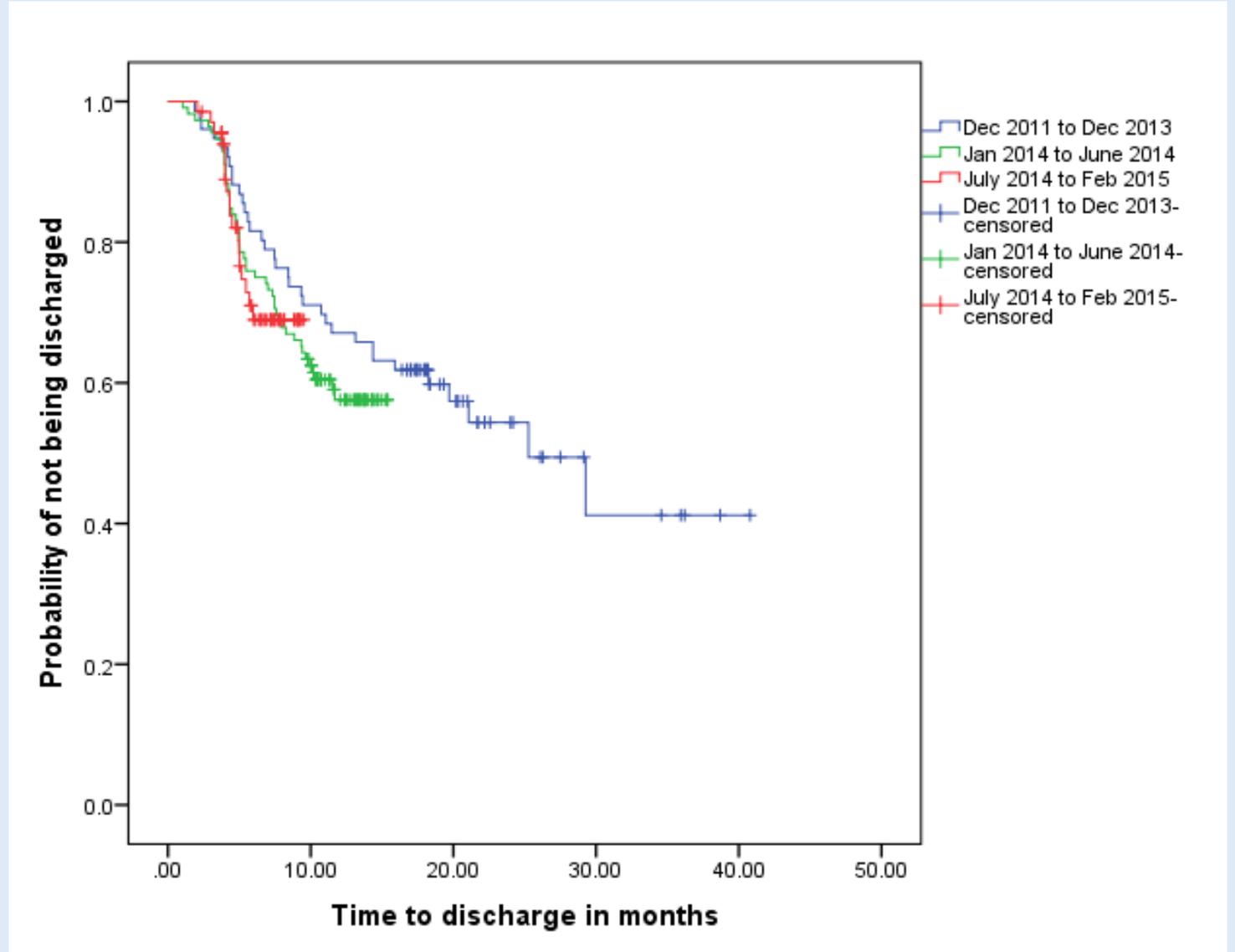
# Time to discharge at a dermatology clinic

## Patients referred

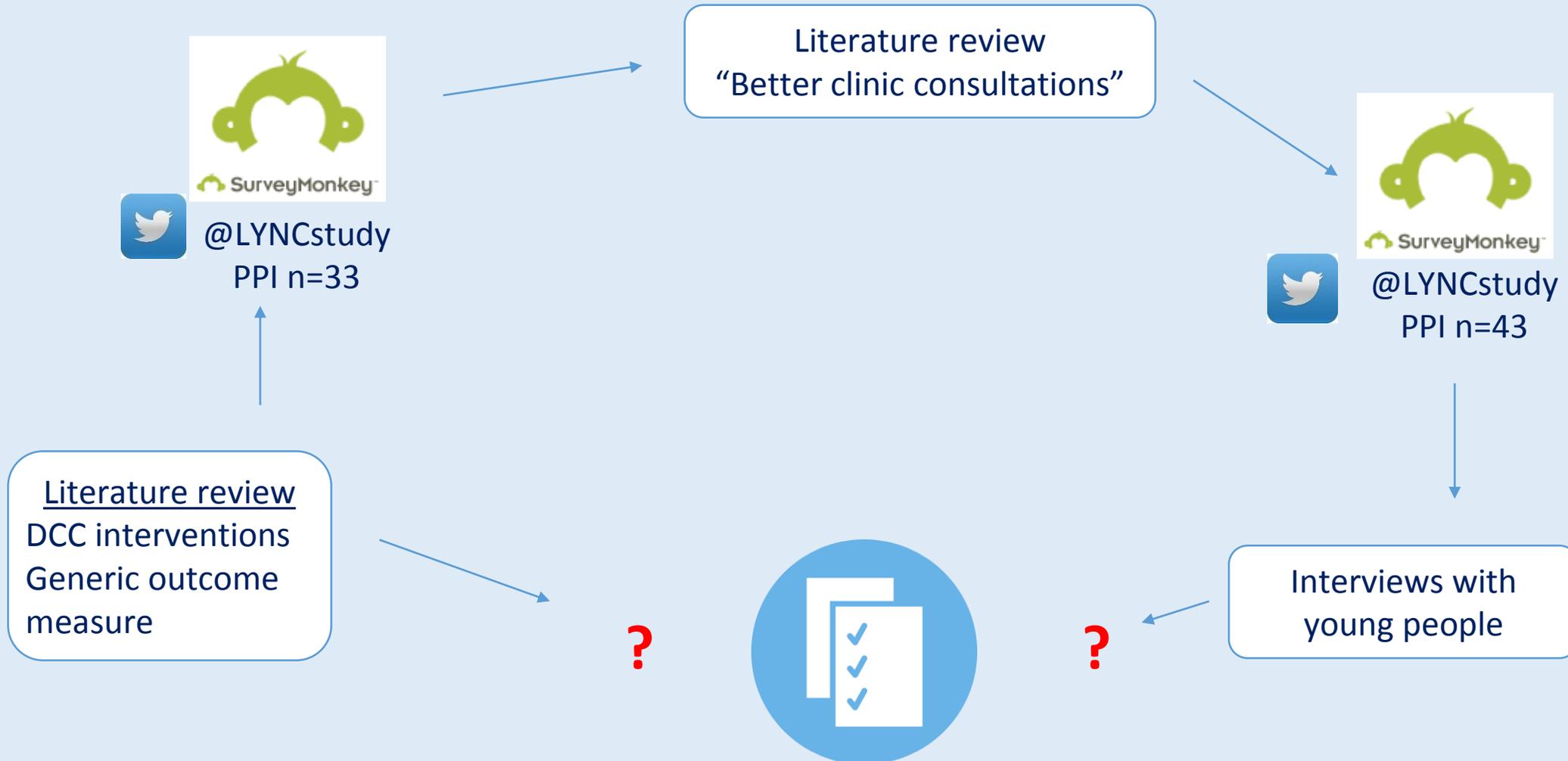
Dec 2011 – Dec 2013  
n = 76

Jan 2014 – June 2014  
n = 169

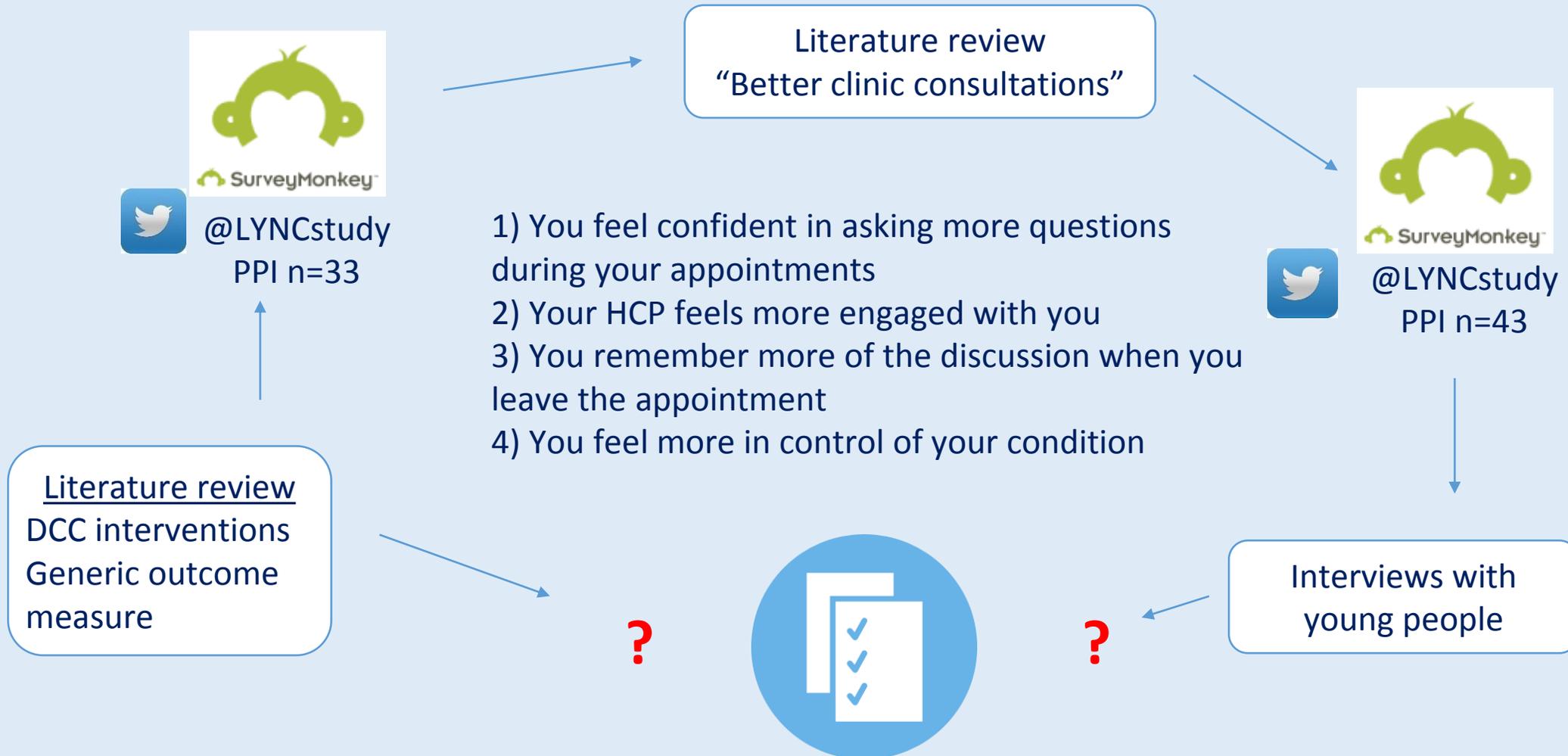
July 2014 – Feb 2015  
n = 84



# Problem: Need for a generic outcome measure for DCC



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### **Collaborating Organisations:**

University of Warwick, King's College London, University of Oxford, University Hospitals Coventry and Warwickshire NHS Trust, King's College London NHS Trust, Guy's and St Thomas' NHS Trust

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### **Department of Health Disclaimer:**

The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.

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## Example of the mixed methods data analysis approaches being developed

Clinic ●	Greatest to least DCC activity	DNA	A&E	Admission	Clinical	Ethical concerns /issues	Safety concern/ issues	Estimates of cost
1	All clinicians use email and text with majority of young people. At least 3 DCC team member communications with each person between clinic appointments. All team have NHS smart phones. On call rota for managing out of hours DCC. IG policy ambitious and brave	?	?	?	?	?	?	£
2								
3								
4								
5								
6								
20	No NHS supported DCC phones. Lone clinician occasionally emails from personal phone to 2-3 young people, no team communication or culture around this. No IG policy	?	?	?	?	?	?	£