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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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

- Measuring effectiveness
- Health outcomes?
- Risks and harms?
- Demographic Issues?
- Not future focused
- Content of communication?
- Impact on service use?
- Implementation and roll out
- Across clinical conditions
- Training and preparation
- Resource implications
- Moderators & mediators?
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**

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

### Presenting data today from:
- **Diabetes**
- **Dermatology**
- **Liver clinics**

### Presenting data today on:
- **What works**
- **Ethics**
- **Outcomes**
- **Health economics**
- **PPI activity on measuring DCC effectiveness**
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

<table>
<thead>
<tr>
<th>Concerns</th>
<th>Answers</th>
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<tbody>
<tr>
<td>What concerns do patients and clinicians have about confidentiality?</td>
<td>• Confidentiality</td>
</tr>
<tr>
<td>How does DCC affect the patient/clinician relationship and the clinician’s duty of care?</td>
<td>• Increasing Autonomy</td>
</tr>
<tr>
<td>What regulatory framework is needed to reassure patients and clinicians regarding its use?</td>
<td>• Better relationships</td>
</tr>
</tbody>
</table>
**Ethical analysis - Health professionals**

<table>
<thead>
<tr>
<th>Questions</th>
<th>( \text{Managing patient privacy} )</th>
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<tbody>
<tr>
<td>What concerns do patients and clinicians have about confidentiality?</td>
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<tr>
<td>How does DCC affect the patient/clinician relationship and the clinician’s duty of care?</td>
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<td>What regulatory framework is needed to reassure patients and clinicians regarding its use?</td>
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<tr>
<td></td>
<td>Managing professional boundaries</td>
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<td>Increasing Autonomy</td>
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</table>
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

Literature review
DCC interventions
Generic outcome measure

@LYNCstudy
PPI n=33

Literature review
“Better clinic consultations”

@LYNCstudy
PPI n=43

Interviews with young people

? ?
Problem: Need for a generic outcome measure for DCC

Literature review
“Better clinic consultations”

@LYNCstudy
PPI n=33

1) You feel confident in asking more questions during your appointments
2) Your HCP feels more engaged with you
3) You remember more of the discussion when you leave the appointment
4) You feel more in control of your condition

@LYNCstudy
PPI n=43

Interviews with young people

Literature review
DCC interventions
Generic outcome measure
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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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**

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Greatest to least DCC activity</th>
<th>DNA</th>
<th>A&amp;E</th>
<th>Admission</th>
<th>Clinical</th>
<th>Ethical concerns /issues</th>
<th>Safety concern /issues</th>
<th>Estimates of cost</th>
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<tbody>
<tr>
<td>1</td>
<td>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</td>
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<td>20</td>
<td>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</td>
<td>?</td>
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<td>£</td>
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