The role of digital communication in patient–clinician communication for NHS providers of specialist clinical services for young people [the Long-term conditions Young people Networked Communication (LYNC) study]: a mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

The LYNC study

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Scientific summary

Background

Young people (aged 16–24 years) with long-term health conditions tend to disengage from health services, resulting in poor health outcomes. They are prolific users of digital communications and use it for health care. Innovative clinicians in the UK NHS are using digital means to communicate with these young people about clinical issues. There are plans for the NHS to use digital communication with patients more widely.

Published evidence on the use of digital communication for health care include many technology- or disease-specific systematic reviews. These suggest that the use of digital communication may improve health outcomes, but recommend that research be undertaken across disease areas to address identified evidence gaps: how digital communication affects health-care experience and outcome, cost and resource use, risks and harms.

Research question, aims and objectives

The overall research question was: what are the effects, impacts, costs and necessary safeguards for digital clinical communications (DCCs) for young people living with long-term conditions (LTCs) and engaging with specialist NHS providers?

The research aims were to:

- evaluate the impacts and outcomes of DCCs for young people living with a LTC
- provide a critical analysis of the use, monitoring and evaluation of DCCs by NHS providers.

The objectives were to:

- engage young people in the implementation of the research
- observe and explore with young people with LTCs – and where appropriate a parent/carer, clinicians and managers – the use of DCC in the NHS for a variety of clinical conditions, how it is used and with what impact and issues related to ethics and patient safety
- investigate the impact of DCCs on health outcomes for young people with LTCs and on their engagement with, and use of, health services
- describe the cost of implementation and ongoing provision of DCC and how it varies across different clinical conditions and to understand the value of this service to patients and clinicians
- identify and explore the use of patient-reported outcome measures (PROMs) for future cost-effectiveness studies, which can be used across disease areas to capture the impact of DCC
- evaluate and synthesise published evidence on the use of DCC by health professionals with young people with LTCs
- develop and disseminate guidance for NHS providers and commissioners on the use of DCC, to provide insights for policy-makers from current NHS use of DCC and to consider the need for future research.

Methods

Patient and public involvement activity

Two events, each of 2 days' duration, were run with school pupils who undertook mini-projects to capture the perspectives of their peers on DCC. Young people beyond school age were engaged via social media to provide their perspective on potential PROMs. The Project Management Group was chaired by the patient and public involvement (PPI) co-applicant and five further PPI representatives were members.

Empirical study

This was an observational mixed-methods case study undertaken in the UK NHS.

One hundred and four clinical teams were identified as potential case studies, of which 47 were eligible and interested in participating. Twenty teams were sampled purposively for diversity of clinical condition, DCC use, size and geographical location.

Inclusion criteria for case studies were that the clinical team was providing specialist care for young people (aged 16–25 years) with LTCs; the clinical team had an interest in the use of two-way digital communications with the young people; and the LTC had considerable cost implications for the NHS.

Clinical teams and the young people variously used the following media for DCC: mobile phone calls, text messages, e-mail and voice over internet protocol (VoIP). Three clinical teams used no digital communication with their young people.

Observation was undertaken with 79 staff drawn from across all clinical teams during their day-to-day work. Interviews were undertaken with 165 young people, aged 16–24 years, living with one of 13 different long-term physical or mental health conditions; 13 of their parents; 173 clinical team members providing care for the young people from across all sites; and 16 information governance (IG) officers from 11 provider organisations. A questionnaire completed by 109 staff from across 17 sites provided health economic data.

Evidence of each clinical team's own evaluation of their use of DCC was sought. The following routinely collected aggregate data were extracted: did not attend, accident and emergency attendance and hospital admission rates for young people cared for by each clinical team, along with a clinic-specific clinical outcome.

Observation data were recorded as written notes at the time of observation then typed up and expanded immediately after observation and reflective notes made. Interviews were audio-recorded and reflective notes made after each interview. Recordings were transcribed and notes typed up and expanded. Transcriptions were checked for accuracy against recordings. All qualitative data were coded for the different analysis approaches within the project (what works for whom, where, when and why; ethics; patient safety; health economics). The IG officer interviews were coded and analysed separately as these interviews covered the use of DCC in the whole NHS trust in which the specialist worked, not just the clinic we had studied.

Independent coding was undertaken on 20% of all coding and discrepancies discussed. Quality checks were undertaken on data entry of survey data. Routinely collected aggregate data were checked on receipt for its completeness.

For 'what works for whom, where, when and why', ethics and patient safety and health economics qualitative data were analysed thematically. Survey data were analysed for annual direct costs associated with DCC usage. Routinely collected data were analysed for trend across time.

Review of potential generic measures available to assess the impact of digital clinical communication

A systematic review of published literature for PROMs used in the evaluation of DCC was undertaken followed by a social media-supported consultation with PPI representatives on their appropriateness. A further structured literature review, informed by empirical study findings, was used to identify relevant PROMs which were reviewed by PPI representatives and tested in cognitive interviews.

Evidence reviews

Five systematic scoping reviews and one review of reviews were undertaken on the use of DCC of any type with young people within the following topic areas: mental health (CRD42016038792), diabetes mellitus, physical health conditions (excluding diabetes mellitus), involvement of parents and carers (CRD42016035467), use of VoIP media and use in countries with or moving towards universal health coverage (excluding literature included in the other reviews).

Searches were undertaken for peer-reviewed literature published from 2009 onwards in English (except for the review of literature from countries with or moving towards universal health coverage when searches were expanded to include non-English-language literature) and of any study/review design. Study/review participants had to include young people aged between 16 and 25 years (or 0–25 years for parent/carer review) living with a LTC.

For the systematic scoping reviews, patient, health professional and health service delivery outcomes were reported along with technical problems. Papers were checked for quality and data extracted into a standardised format, with independent checks by another reviewer. Results were summarised narratively and in summary tables.

Developing guidance for NHS providers and commissioners and providing insights for policy-makers

As project results started to emerge, consultation meetings were held with NHS Digital (formerly the Health and Social Care Information Centre) and NHS England. From our initial results they identified the following needs:

- an understanding of the use of personal health records (PHRs) within the NHS
- an understanding of IG officer perspectives on the use of Skype™ (Microsoft Corporation, Redmond, WA, USA) in their NHS trusts
- results of the study in a format accessible to front-line clinicians.

Six case sites had platforms able to support some of the features of a PHR. Data from these sites were reinterrogated for how this record was being used, and the views of staff and young people summarised for each case site. The 16 IG officer interviews were reinterrogated for data on views and use of Skype and were then analysed thematically. Study results were summarised into 10 themes and study PPI representatives provided feedback on these quick reference guides.

A consensus conference was held to externally validate the quick reference guides, to agree on how they can be used to support any planning or provision of DCC within the NHS and on their transferability to other patient populations. Clinicians, service users, patient advocates and IG/technology professionals were invited via digital communication channels. Forty-nine people attended, and participated in, focus group discussions. Notes were taken and summarised thematically.

Results

Digital access for young people with LTCs to the right clinician at a time when it will make a difference to how they manage their condition – with response times between a few minutes to a few days depending on the health condition – is valued by young people and clinicians. This timely communication can enhance the experience of health care through timely access to information and advice for young people with LTCs. It is valued by the young people and their care providers as an addition to traditional clinic appointments. Clinicians and young people variously use mobile phones, text messages, e-mail, VoIP and PHR systems.

This access challenges the nature and boundaries of the therapeutic relationship. Digital communication was convenient for clinicians and young people, particularly asynchronous communication, but there is qualitative evidence that its use also improved relationships between young people and clinicians, increased patient empowerment and autonomy, enhanced activation and prompted better self-management. There was also evidence of wider benefits in well-being.

Risks from the use of DCC for timely access include increased dependence on clinicians and disempowerment of the young people. The ease and speed of use of digital media magnifies risks relevant to all forms of clinical communication: gaining consent, inadvertent disclosure of confidential information, communication failures, failure to record the communication in clinical notes and failure to consult clinical notes. There is variation in whether or not, and how, clinicians mitigated these risks in their clinical context. There was also variation in application of service provider policy on consent and confidentiality. There was a recognition among IG officers of the need for clinician training.

Providing timely digital access to clinical advice and support increases workload and rarely replaces traditional in-person consultations, but can improve their value for clinicians and young people, particularly PHRs or similar systems in which clinical data were exchanged. The economic costs are mostly for staff time. There was also concern that this activity was not fully recorded. There may be some saving in opportunity costs but this was difficult to quantify. The potential benefits of improved self-management and well-being among the young people is likely to save NHS costs in the long term.

None of the clinical teams studied had undertaken their own evaluation of the impact of the use of DCC on their young people. Analysis of routinely collected data did not reveal effects on health outcomes. However, pathways to impact, such as improved well-being and reduced complications from the LTC, were identified. There is no currently used generic outcome measure for DCC. However, the Patient Activation Measure and the Physicians' Humanistic Behaviours Questionnaire are promising candidate measures.

The five systematic scoping reviews and one review of reviews all suggest that DCC is acceptable to young people and their carers. The evidence suggests no clear benefit to health outcome from its use except for mental health conditions, although the reviews did not distinguish between provision of replacement and additional service.

There was consensus that the results of this study are transferable to other health-care settings, particularly where a clinical team has an ongoing relationship with a patient with a LTC.

Conclusions

Timely DCC is perceived as making a difference to the experience of health care and health outcomes for young people with LTCs, although this is not yet supported by evidence measuring health outcomes. It is likely that evaluation of DCC requires measurement of modifiers of health outcome rather than health outcome itself, as impact on health outcome may be beyond the timescale of most studies.

The provision of timely DCC is costly and challenging to provide. There are risks, many of which can be mitigated by relevant technology such as encrypted e-mail, clinical system design, clinical team protocols and training.

If clinical teams develop a business case for the use of digital communication, it is helpful to clarify the degree to which the digital communication will be additional to traditional provision or a replacement. As digital communication becomes the norm in society generally, replacement of some aspects of traditional clinical communication with digital may be important for maintaining health service access for the digital generations.

Qualitative data were collected from clinician enthusiasts and so may not reflect the perspectives of clinicians more generally. Interviews did not elicit explicit ethical reflection. No interviews were achieved with young people who failed to engage with their clinical team. Clinicians found it difficult to estimate workload. Only eight clinical teams provided full sets of routine data.

Further research is needed to:

- test relevant PROMs for use in evaluating DCC
- evaluate, with an experimental design, the impact of timely DCC for people living with LTCs
- explore and evaluate the benefits and disbenefits of replacing traditional clinical consultations with digital communication
- evaluate the impact of the changing digital landscape on how it is best to use DCC to achieve its aims in an ethical, safe and cost-effective way.

Study registration

Two of the reviews in this study are registered as PROSPERO CRD42016035467 and CRD42016038792.

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