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

Frances E Griffiths,1* Xavier Armoiry,1 Helen Atherton,1 Carol Bryce,1 Abigail Buckle,1 Jonathan AK Cave,2 Rachel Court,1 Kathryn Hamilton,3 Thandiwe R Dliwayo,3 Melina Dritsaki,1 Patrick Elder,1 Vera Forjaz,3 Joe Fraser,4 Richard Goodwin,3 Caroline Huxley,1 Agnieszka Ignatowicz,1 Eleni Karasouli,1 Sung Wook Kim,1 Peter Kimani,1 Jason J Madan,1 Harjit Matharu,5 Mike May,1 Luhanga Musumadi,6 Moli Paul,7 Gyanu Raut,8 Sailesh Sankaranarayanan,5 Anne-Marie Slowther,1 Mark A Sujan,1 Paul A Sutcliffe,1 Isabelle Svahnstrom,1 Frances Taggart,1 Ayesha Uddin,1 Alice Verran,1 Leigh Walker1 and Jackie Sturt3

1Warwick Medical School, University of Warwick, Coventry, UK
2Department of Economics, University of Warwick, Coventry, UK
3Florence Nightingale Faculty of Nursing and Midwifery, King’s College London, London, UK
4Patient and public involvement representative, London, UK
5University Hospitals Coventry and Warwickshire NHS Trust, Coventry, UK
6Guy’s and St Thomas’ NHS Foundation Trust, London, UK
7Coventry and Warwickshire Partnership Trust, Coventry, UK
8King’s College Hospital NHS Foundation Trust, London, UK

*Corresponding author  f.e.griffiths@warwick.ac.uk
Declared competing interests of authors: Frances E Griffiths and Anne-Marie Slowther are funded for other research by the National Institute for Health Research (NIHR) Health Services and Delivery Research programme (14/156/20 and 13/10/14), the NIHR Programme Grants for Applied Research programme (RP-PG-1212-20018) and the NIHR Research Design Service (PR-RD-0312-1001).

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

**Funding**

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.
Health Services and Delivery Research

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the Health Services and Delivery Research journal
Reports are published in Health Services and Delivery Research (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme
The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hsdr

This report
The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 12/209/51. The contractual start date was in May 2014. The final report began editorial review in August 2016 and was accepted for publication in April 2017. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care.

© Queen’s Printer and Controller of HMSO 2018. This work was produced by Griffiths et al. under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).
*Health Services and Delivery Research Editor-in-Chief*

**Professor Jo Rycroft-Malone**  Professor of Health Services and Implementation Research, Bangor University, UK

*NIHR Journals Library Editor-in-Chief*

**Professor Tom Walley**  Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

*NIHR Journals Library Editors*

**Professor Ken Stein**  Chair of HTA and EME Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

**Professor Andrée Le May**  Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals)

**Dr Martin Ashton-Key**  Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

**Professor Matthias Beck**  Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

**Dr Tessa Crilly**  Director, Crystal Blue Consulting Ltd, UK

**Dr Eugenia Cronin**  Senior Scientific Advisor, Wessex Institute, UK

**Dr Peter Davidson**  Director of the NIHR Dissemination Centre, University of Southampton, UK

**Ms Tara Lamont**  Scientific Advisor, NETSCC, UK

**Dr Catriona McDaid**  Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

**Professor William McGuire**  Professor of Child Health, Hull York Medical School, University of York, UK

**Professor Geoffrey Meads**  Professor of Wellbeing Research, University of Winchester, UK

**Professor John Norrie**  Chair in Medical Statistics, University of Edinburgh, UK

**Professor John Powell**  Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

**Professor James Raftery**  Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

**Dr Rob Riemsma**  Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

**Professor Helen Roberts**  Professor of Child Health Research, UCL Institute of Child Health, UK

**Professor Jonathan Ross**  Professor of Sexual Health and HIV, University Hospital Birmingham, UK

**Professor Helen Snooks**  Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

**Professor Jim Thornton**  Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

**Professor Martin Underwood**  Director, Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of members of the NIHR Journals Library Board:  
www.journalslibrary.nihr.ac.uk/about/editors

**Editorial contact:** journals.library@nihr.ac.uk