

# Patient and carer survey of remote vital sign telemonitoring for self-management of long-term conditions

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## ABSTRACT

**Background** Home-based self-monitoring has failed to show intended savings to healthcare budgets yet it continues to emerge and gain popularity.

**Objective** We set out to verify stakeholders' perspectives of remote vital sign telemonitoring.

**Design** An observational design was adopted by devising a survey for distribution to service users and their informal carers.

**Sample** Service users in South Eastern Health and Social Care Trust were included. A total of 274 questionnaires were issued. Data from 97 patients (35% response rate) and 49 carers were analysed. Of these, 81 patients and 48 of their carers experienced a monitoring service known as TF3 and 16 patients and 1 carer experienced a service known as U-Tell. The cohorts comprised people living with a number of long-term conditions: diabetes, hypertension after stroke, chronic heart failure, chronic obstructive pulmonary disorder, bronchiectasis and those requiring anticoagulation using warfarin.

**Results** Analysis showed that respondents were supportive of the technology with 90.7% of patients agreeing or strongly agreeing with the statement: *the remote monitoring system assisted me in managing my health on a day-to-day basis*. The patients liked the technology largely because it provided empowerment and control for self-management and allowed them to continue with their lives without major disruption. These views were independent of the technology used and not associated with the patient's long-term conditions, gender or age. There were no reported adverse incidents.

**Conclusion** As self-monitoring becomes more relevant to healthcare delivery, the technology will be accepted by many in the population with long-term conditions.

## INTRODUCTION

Managing long-term conditions provides significant pressures within most healthcare systems. The WHO reported that circa 38 million deaths per year were due to non-communicable diseases; their Global Action Plan 2013–2020<sup>1</sup> aimed to reduce such deaths by 25% by 2025. One approach to enhanced management has been to adopt telehealth, in particular the application of remote vital sign telemonitoring (RVT) which avails of advances in near patient testing, computer technology and communications.

## Summary

### What is already known?

► Remote vital sign telemonitoring has been difficult to introduce into mainstream health service provision, due to the lack of convincing evidence. A whole-system demonstrator trial was undertaken in England and Wales, but findings were equivocal, regardless of the metric of interest (readmission, value for money). In Scotland, a large study, of people living with chronic obstructive pulmonary disease, reported mainly negative findings with regards to readmission (which increased). In Northern Ireland, a large regional trial of telemonitoring was introduced in 2011 but discontinued when the regional contract was not renewed in 2018. However, a previous study indicated that patients largely approved of the telemonitoring.

### What does this paper add?

► We collected detailed feedback from 97 patients and 49 carers in South Eastern Health and Social Care Trust. We found that self-monitoring of long-term conditions was readily accepted by most patients and the technology provided empowerment for both patients and carers. Our findings were not technology dependent and not condition specific. The participation rate was 35%. However, a weakness of our approach is that the respondents may have been more supportive of the intervention than those who did not respond.

► Many patients with long-term conditions and their carers will support the introduction of RVT for self-management. Even if the uptake rate of RVT is commensurate with the survey response rate (ie, 35%), it can lead to a disruptive approach to managing long-term conditions: patients tend to benefit from the support provided.



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Reviews have synthesised the findings of RVT studies for self-management, professional practice and support of carers. Hitherto findings have been largely negative.<sup>2–4</sup> However McClean *et al* suggested that RVT provided an opportunity for patient education, improved adherence of medication and a positive effect on a patient's quality of life.<sup>4</sup> In England and Wales, the whole-system

demonstrator (WSD) programme attempted to integrate telehealth into practice. Steventon and Bardsley<sup>5</sup> examined hospital utilisation via emergency admissions and mortality. Findings suggested a 20% reduction of emergency admissions and a statistically significant difference with deaths, with 4.6% of participants in the WSD intervention arm versus 8.3% of control participants. However, the review did not offer explanation as to why or how the intervention improved the outcome based on the metrics considered. A cost-effectiveness study<sup>6</sup> of the WSD programme did not make the case for telehealth. The study suggested that cost burden was borne by community services, whereas cost benefit was realised by secondary care and suggested a rebalance. Pinnock *et al*<sup>7</sup> examined the effectiveness of telemonitoring as defined by the admission rates when compared with usual care for patients with chronic obstructive pulmonary disease (COPD). The study did not show effectiveness and hypothesised that earlier positive findings could have been due to the enhancement of underpinning care provision rather than telehealth. A description of the understanding of their condition and appreciation of the intervention by participants, arguably demonstrated empowerment. However, Hanlon *et al*<sup>8</sup> caution that existing findings could be outdated due to technology advances and the nature of meta-analysis.

In 2011 in Northern Ireland, the Public Health Agency contracted a consortium known as TF3, comprising Tunstall Healthcare, Fold Telecare and S3 Group to provide telemonitoring across the region.<sup>9</sup> This service was monitored by specialist nurses and allied health professionals. Management was undertaken of (up to) 1000 patients (in all trusts) with diabetes, COPD, chronic heart failure (CHF) and hypertension in post-stroke. Sensing devices were used by patients (assisted as appropriate by carers) to capture relevant vital signs, and a home hub transferred the data to a monitoring service. Two types of monitoring were provided: (1) track and trend, data were recorded by the monitoring service, but clinical care was undertaken by the patient's own care team and (2) triage, the patient was monitored by the TF3 clinical triage team.

In the South Eastern Health and Social Care Trust (SET), one of five Trusts in Northern Ireland, where this research study was undertaken, an additional home telemonitoring project called U-Tell was trialled.<sup>10</sup> This comprised a Roche CoaguChek device and web portal, which enabled patients who administered oral anticoagulation medication to undertake testing of capillary blood at home and transmit their international normalised ratio (INR) readings to the nurses at Ulster Hospital's haematology department. This reduced the need to attend outpatients for a venous sample of blood to be taken and tested in the laboratory.

The objectives of this study were the following: (1) to survey and evaluate patients and carers to obtain stakeholder perspectives and (2) to understand user perceptions for acceptance of RVT.

## METHODS

An observational design was used involving patient and carer surveys. As part of a mixed-methods study, the quantitative survey data were synthesised with qualitative data derived from clinical practitioners, commissioning and operational managers. The qualitative data were collected through semistructured interviews and the quantitative data through questionnaires posted to the target cohort. The questionnaires permitted a respondent to add unstructured qualitative data/narrative.

The patient population actively interacting with RVT was included. This contained seven disease subgroups and two RVT technologies with three service deployment models. By the inclusion of the entire SET RVT case load, it was assumed that the findings would be less likely to be skewed or inadvertently unrepresentative of participants' views. Users consisted of patients experiencing combinations of service reflecting medical conditions, including heart conditions, diabetes, respiratory issues, weight control, warfarin anticoagulation therapy and hypertension/high blood pressure in poststroke patients. The differing conditions meant that practitioners selected RVT devices to meet particular clinical observation needs.

In advance of the formal study, patients and carer questionnaires were prototyped and modified by the lead researcher to enable further enquiry and tracking of service perception over time. The questions focused on benefits, risks, care, application of technology and service user recommendations to practitioners. Advice was received and enacted following feedback from an independent review of the Patient and Client Council in Northern Ireland.

The proposal was scrutinised through peer review at Ulster University (Project No: 15/0065). The Proportionate Review Sub-Committee of the Health Research Authority, National Research Ethics Service Committee South Central—Oxford C (Integrated Research Application System (IRAS) project ID 155990, 15 July 2015) gave a favourable opinion. SET Research Governance was obtained on 11 August 2015 (REC 15/SC/0424 Trust ref SET/15/17). There were no serious risks associated with participation or data collection.

Participant information sheets and prepaid return envelopes were posted with the questionnaires (1 September 2015). This comprised 274 questionnaires. Where an informal carer played a role in RVT, they were also invited to provide data from their perspective. Completed questionnaires were returned to the Safe and Effective Care team, compiled and made available to the researcher. A unique alphanumeric code on each questionnaire enabled anonymisation. The file containing participant study identification codes and personal details was kept secure in a password-controlled computer system. Paper copies of the surveys were kept in a secure location. Confidentiality was respected but was not guaranteed, for example, if an adult safeguarding issue was identified. Any disclosure of poor practice would have followed normal management and research governance protocols. During

**Table 1** Mean age profile of respondents by reported condition: in most cases, RVT was used with older people: maternity services and weight management engaged younger users

Condition	Mean age (SD)	Monitoring
Diabetes	70.2 (10.9)	TF3: Home hub (a device to collect data and send it to a remote computer), blood glucose, BP
COPD (respiratory)	71.2 (8.8)	TF3: Home hub, temperature, BP, SpO2
Bronchiectasis (respiratory)	69.7 (4.6)	TF3: Home hub, temperature, BP, SpO2
Stroke	67.5 (14.8)	TF3: Home hub, BP
Chronic heart failure	81.7 (6.2)	TF3: Home hub, BP, weight, 3-lead ECG
Hypertension	72.0 (10.3)	TF3: Home hub, BP
Dementia	78.0	Reported by respondents but <b>not</b> managed in TF3 service
Renal disease	69.0	Reported by respondents but <b>not</b> managed in TF3 service
Weight management	56.2 (24.1)	TF3: Home hub, weight
Maternity	44.3 (15.0)	TF3: Home hub, weight
INR	65.4 (11.9)	CoaguChek and web portal Reported by two TF3 respondents but <b>not</b> managed through TF3 service. 16 INR patients were monitored by SET through U-Tell

bp, blood pressure; COPD, chronic obstructive pulmonary disease; INR, international normalised ratio; RVT, remote vital sign telemonitoring; SET, South Eastern Health and Social Care Trust; SpO2, oxygen saturation.

the analysis no such issues were recorded; no individual patient's personal information was accessed or identified.

This study considers the analysis of the quantitative data provided by both patients and carers. Data were transferred into SPSS V.25. Once the data were validated, hypothesis testing was undertaken and independent t-tests were calculated.

## RESULTS

The RVT service was designed to support care for patients with long-term conditions. TF3 was used to monitor diabetes, respiratory conditions, hypertension or CHF, U-Tell for INR/warfarin management. A total of 242 questionnaires were issued to patients (and carers) with the TF3 system; 81 (33.5%) patient and 48 carer questionnaires were returned. In addition, 32 questionnaires were

issued to patients (and carers) with the U-Tell system; 16 patients (50%) and 1 carer questionnaires were returned. There were 97 patient respondents, 83.5% of whom used the regionally commissioned TF3 service. There was an approximate gender balance of patients (49 males and 39 females, 9 did not respond). The mean age of patients was 68.8 years (69.5 years for TF3 and 64 years for U-Tell); refer to [table 1](#).

COPD and bronchiectasis were classified as 'respiratory'; the service received by a patient whether they had COPD or bronchiectasis or both was the same. TF3 reported the readings via Bluetooth (wireless connection) from peripheral devices to the practitioners through a Home hub, whereas U-Tell used a web-based interface which relied on self-reporting of data from the peripheral device.

**Table 2** Reliability of each of the empowerment questions within the questionnaire

The remote monitoring system ...	Scale mean	Scale variance	Corrected item: total correlation	Cronbach's alpha (range 0–1)
Assisted me in managing my health on a day-to-day basis	21.43	10.158	0.722	0.904
Reduced the number of health professional visits	21.61	9.241	0.828	0.891
Prevented or reduced need to attend outpatient appointments	21.78	9.055	0.715	0.906
Has helped me manage my own condition and become involved in healthcare	21.63	9.783	0.699	0.905
Has given peace of mind	21.51	10.405	0.678	0.908
Has reduced number of GP visits	21.58	9.308	0.817	0.893
Has prevented the need to attend emergency department and/or GP out-of-hours service	21.72	8.843	0.767	0.899

GP, general practitioner.

**Table 3** Responses to the question: ‘Has helped me manage my own condition and become involved in my healthcare’

Condition	Mean rating (SD)	Condition incidence reported by patients
Diabetes	3.0 (0.85)	15
COPD	3.49 (0.68)	59
Bronchiectasis	3.78 (0.44)	9
Stroke	1.5	2
Chronic heart failure	3.17 (1.17)	6
Hypertension	3.17 (0.49)	7
Dementia	1	1
Renal	4	1
Weight management	3.17 (0.75)	6
Maternity	3.00 (1.00)	3
INR	3.67 (0.49)	18

COPD, chronic obstructive pulmonary disease; INR, international normalised ratio.

To determine if there was any perceived patient benefit, seven questions were posed; [table 2](#) shows mean, variance and correlation as determined by SPSS. The Cronbach’s alpha statistic of over 0.70 for each question shows that the responses are consistent and may be regarded as reliable.

The question: ‘Has helped me manage my own condition and become involved in my healthcare’ is indicative of empowerment. [Table 3](#) enumerates responses rating (4 being the high rating attributed to the value statement, ‘strongly agree’ and 1 being the low rating attributed to the value statement, ‘strongly disagree’).

There were some inaccuracies in the demographic data, as well as the existence of comorbidity, so that the total number of conditions recorded exceeded the number of participants. A factor to consider was that some patients disclosed conditions for which they were not supported through RVT. Ninety-seven participants recorded 127 conditions, refer to [table 3](#). While the care options for the conditions of dementia and renal were available in other trusts, they were not used in SET. Furthermore, the weight management service and maternity service in SET was a single service managed by a dietitian. Some patients received RVT to manage two or more long-term conditions and hence reported comorbidities. To prevent skewing of results, each participant’s rating for a question was included once. Where there were differences in opinion between patient groups, there may be a risk of comorbidity skewing findings.

[Table 3](#) considers if the patient opinions varied according to their condition when responding to the question: ‘Has helped me manage my own condition and become involved in my healthcare’. The lowest rating of 1 was recorded by one participant, who documented a

dual diagnosis including dementia; this syndrome was not supported by RVT so their rating would also be allocated against the condition for which they were prescribed RVT. Equally, one participant recorded a renal diagnosis and a rating of 4. Again, RVT for renal was not supported and so it is recognised that the rating was also attributed to the condition for which they were prescribed RVT. Such dual attribution of rating demonstrated a potential skewing of findings when mean rating is calculated against a diagnostic variable rather than against a technology, a gender or simple participant count. This is because there were more conditions recorded than patients and where comorbidity exists, there may be bias with the mean rating. Consideration of the mean rating by condition was of interest as it was used to gauge if there was a generalisable difference between the experience of people who were monitored for different conditions. No significant difference was found. There were circumstances where the number of patients reporting a condition was low. For example, two patients recorded a diagnosis of stroke where the mean rating for two participants was 1.50. These patients were referred by the stroke specialist nurse for the monitoring of their blood pressure and so equally their rating would be reflected in the mean rating for hypertension, a condition that was recorded seven times. The low rating by patients with stroke was consistent with qualitative data provided by the stroke practitioner in a separate data collection exercise. Eighteen patients reported that they had taken warfarin; but only 16 patients were managed through the U-Tell system. The mean rating was 3.67.

The distribution of responses versus score for the question: ‘Has helped me manage my own condition and become involved in my healthcare’ is shown in [figure 1](#). For 93 valid responses, the mean value was 3.52 with a SD of 0.636.

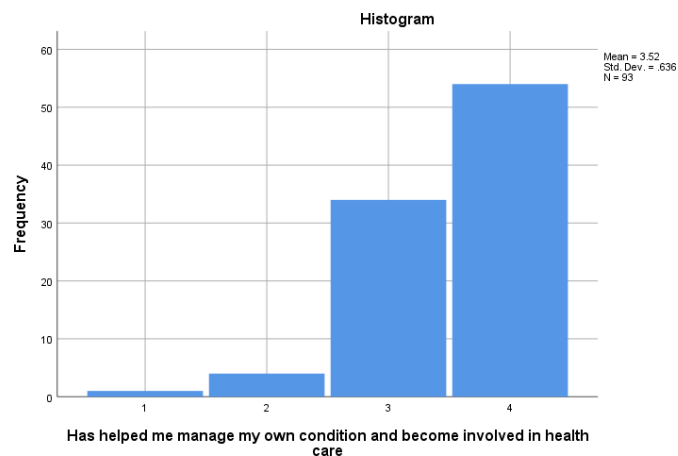
Responses given by carers were consistent with the opinions expressed by patients. The carers’ mean score of 3.72 attributed to ‘improving the level of care received’ and ‘has given peace of mind’ demonstrates carer support for RVT. The lowest mean score was 3.41 which related to perceived benefit of *future use of internet-based technology*.

## DISCUSSION

RVT interventions have been introduced in the UK primarily to reduce acute admissions and potentially to show economic benefit. By contrast, patient-reported and carer-reported benefit suggest the approach is more about empowerment and enhanced self-management.

An initial survey of 100 patients, undertaken in 2014 by the TF3, had shown that 95% of patients agreed that the service assisted them with better self-management. In view of such potential benefits, McElroy *et al*<sup>11</sup> were commissioned by the Public Health Agency to review the regional TF3 service. Twenty-three service users and carers engaged in focus group activity across Northern Ireland; the authors concluded that patients and carers





**Figure 1** Histogram to demonstrate frequency of responses versus score for patient responses to the question: 'Has helped me manage my own condition and become involved in my healthcare'.

were reassured by and approved of telemonitoring. McDowell *et al*<sup>12</sup> reported a randomised controlled trial for SET TF3 triage service for 150 patients with COPD. In total, 84% of participants agreed that it enabled them to feel more in control of their health on a day-to-day basis; however as with other UK studies, economic benefit was not found.

Our study recruited 97 patients (35% patients with long-term conditions) and 49 carers. In broad agreement with,<sup>11 12</sup> we conclude that there is benefit to RVT patients from their own self-management and proactive involvement; indeed, one respondent wrote, "... because my oxygen levels can drop very quickly and suddenly, I can keep a check on my levels with oxymeter which keeps me from panicking. I can adjust my oxygen accordingly." The ease of use of technology was reported by both patients and carers. However, there was some negative feedback that urges caution. When considering the future use of technology, one carer felt the increased use of the internet would be detrimental and one carer indicated that reliability issues would need to be overcome. One carer suggested that the, "Idea is good, but many older people do not have the technical capability [*or know*] how to use it correctly." However, the majority of RVT patients were over 65 years, reporting they found RVT a simple and helpful solution, so this concern was not representative. These statements highlight key acceptance issues of data privacy, need for enhanced reliability of instrumentation and usability appropriate to cohort. These three issues will remain core to the future acceptance of RVT.

## CONCLUSIONS

A total of 97 patients who used RVT technologies and 49 of their informal carers responded to questionnaires. They provided feedback on how the solutions supported self-care, management and empowerment. There was support across the long-term conditions and across the different types of technology. No significant differences

of opinion were found between different technologies or where different peripheral devices were used. Patient and carer participants were supportive of the use of technology. Patients gave a score of 3.5 (4 strongly agree, 3 agree) to the question: 'Has helped me manage my own condition and become involved in my healthcare'. We interpret this as a proxy for patient empowerment.

In addition to the quantitative analysis, qualitative feedback from participants indicated: ability to live more freely, being in control of their condition, being less anxious and given peace of mind. Of note, while some apprehension was expressed by the patients when first asked by their practitioners to use RVT, the ease of use and general reliability of technology was demonstrated. A feeling of being better connected to their practitioners through technology was expressed. This was counter-intuitive, given the fear of many practitioners, at the introduction of RVT, of detachment from their patients, as articulated in one-to-one interviews.

Patients were empowered to better manage their own conditions in a home environment supported by technology connection with their healthcare practitioners. The participation rate of 35% is appropriate for this survey approach. A weakness is that the respondents may have been more supportive of the intervention than those who did not respond. However, if 35% of people with long-term conditions could successfully adopt RVT for management and the approach was adopted by their clinicians, then enhanced service delivery is possible. Indeed, as the population ages and long-term conditions become more prevalent, RVT could provide the transformation suggested by Bengoa's milestone report into Health and Social Care in Northern Ireland.<sup>13</sup> In page 7, the report suggested that 'to make services higher quality and sustainable, radical transformation is required'. Undoubtedly RVT has a future role if issues with user acceptance are addressed.

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