# An acceptability study for the use of web-based video consultations in patients receiving lifelong treatment for chronic myeloid leukaemia (CML) patients at University College London Hospital (UCLH), London, UK

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# Background

In recent years there has been a rise in offering web-based video consultations in the NHS and private healthcare. In 2015, the Independent Cancer Taskforce recommended a review of "how digital technologies might be used to drive improvements in patient experience", for example by minimising the need for some patients to travel to appointments (Independent Cancer Taskforce, (2015). CML is a chronic cancer and some patients are stable on long term treatment with tyrosine kinase inhibitors (TKIs). Currently patients who have taken TKIs for over 12 months and are stable, attend an outpatient clinic 3-4 times a year as per London Cancer guidelines (London Cancer, 2015). Providing clinical tests were undertaken locally to their home, a video consultation could save such patients travelling to a specialist centre. The potential for pharmacists to support with such a model was identified by a member of the UCLH Cancer Pharmacy team, as the number of Independent Prescribers in the team increased following the publication of the Carter Review in 2016 (DoH, 2016).

A model for remote outpatient consultations could improve patient experience and wellbeing, meeting one of the priorities of the UCLH annual plan for 2016/17 (UCLH NHS Foundation Trust, 2016). Patient experience is measured using the National Cancer Patient Experience Survey (NCPES) survey which is sent to all adult NHS patients, with a confirmed primary diagnosis of cancer, discharged from an NHS Trust after an inpatient episode or day case attendance for cancer related treatment during certain months of the year. The NCPES sample criteria may therefore exclude CML patients who are stabilised on TKI treatment.

This study aimed to see if web-based consultations would be acceptable to CML patients at UCLH with a view to improve overall patient experience. Through this process it was hoped the study would provide a better understanding of how the UCLH team can improve care and overall experience for this group of patients.

# Aim and Objectives

**Aim:** To explore the acceptability of web-based video consultation in patients receiving treatment for CML

**Objectives**

- To identify how web-based video consultations are currently being used in health related consultations between a patient and a healthcare provider
- To outline (an) alternative model(s) for remote follow-up consultations using web-based technology
- To identify current opinions about the review clinic consultation model provided at UCLH for patients receiving treatment for CML

- To establish the review clinic consultations needs of patients receiving treatment for CML
- To understand the patient experience and satisfaction in services in patients with CML, receiving care from UCLH

# Methods

**Study Design**

Following a scoping exercise of current literature, along with further reading and discussions with collaborators, it was decided a mixed methods exploratory and descriptive study using focus groups and interviews alongside a questionnaire would be used. Focus groups and interviews permit a more detailed examination of views and opinions, and a questionnaire evaluating the current patient experience provides a structured method of capturing information relevant to the objectives.

**Research Participants**

The eligibility criteria for interviews and focus group were that participants had to be:

- Aged 18 or above; received TKI treatment for CML for a minimum of 12 months; maintained on the same TKI for 12 months

The exclusion criteria were:

- Patients who lack capacity to consent to the research study, patients who do not speak English and for whom a translator could not be found

**Literature Review: Development of Field Work Materials**

A literature review was conducted to establish existing web-based consultation models for patients with long-term conditions and the results were used to inform the development of the participant questionnaire and interview and focus group topic guides. A full systematic review was not undertaken as the review was to identify models of consultation that currently exist and critical appraisal of research methods and the effectiveness of these models was not being assessed. This review whilst not a full systematic review, was undertaken using the PRISMA 2009 process (PRISMA, 2015) which is summarised in Figure 1. Databases searched included Pubmed; EMBASE, Web of Science and CINAHL. Inclusion and exclusion criteria were identified for the screening process, these are shown in Table 1 along with examples of search terms used. The 17 studies identified were used to inform the development of field work materials, for example: questionnaire design (Anderson *et al*, 2017), potential models of web-based consultations (McGrath, 2015) and interview and focus group guides (Agrell, 2000). In addition to the literature review, a selection of questions from the NCPES which can be seen in Table 4, were chosen to form part of the questionnaire. This was done in

consultation with UCLH cancer pharmacists. The haematology clinical nurse specialist was also consulted about potential consultation models.

**Table 1: Literature Review Screening Criteria and Example Search Terms**

| Example Search Terms | Inclusion Criteria | Exclusion Criteria |
|---|---|---|
| Remote Consultation; Web-based; Skype ; Video; Consultation; Remote; Health; Medical; Telecare; Telehealth; Teleconsultation; Telemedicine; Clinical; pharmacist; pharmacy; Nursing; clinical trials; evidence based practice; Mobile applications; Pharmaceutical services | • Towns, cities and rural<br>• Video communication between patient and health professional<br>• All clinical settings e.g. primary, secondary and Tertiary care<br>• Health services for patients already established to be receiving care and already accessing specialist care<br>• Follow-up services for patients already established to be receiving care<br>• Pharmacists; AND/OR Doctors; Nurses; Dentists<br>• Involved ONE or more of Focus groups; Interviews; Questionnaires OR meta-analysis/review of studies involving these<br>• Evaluation of outcomes: acceptability, feasibility; satisfaction; workability; clinical outcomes | • Telephone consultations<br>• Email consultations/ online text messaging consultations e.g. messenger or typed webchat<br>• Diagnostic/monitoring apps<br>• Diagnosis/triage/ assessment<br>• Preventative medicine<br>• Referral systems<br>• Complementary medicine/ therapies<br>• Treatment of mental health problems<br>• Educational interventions<br>• Surgical interventions<br>• Video consultations carried out at satellite healthcare sites<br>• Video consultations between healthcare professionals<br>• Articles written in a language other than English |

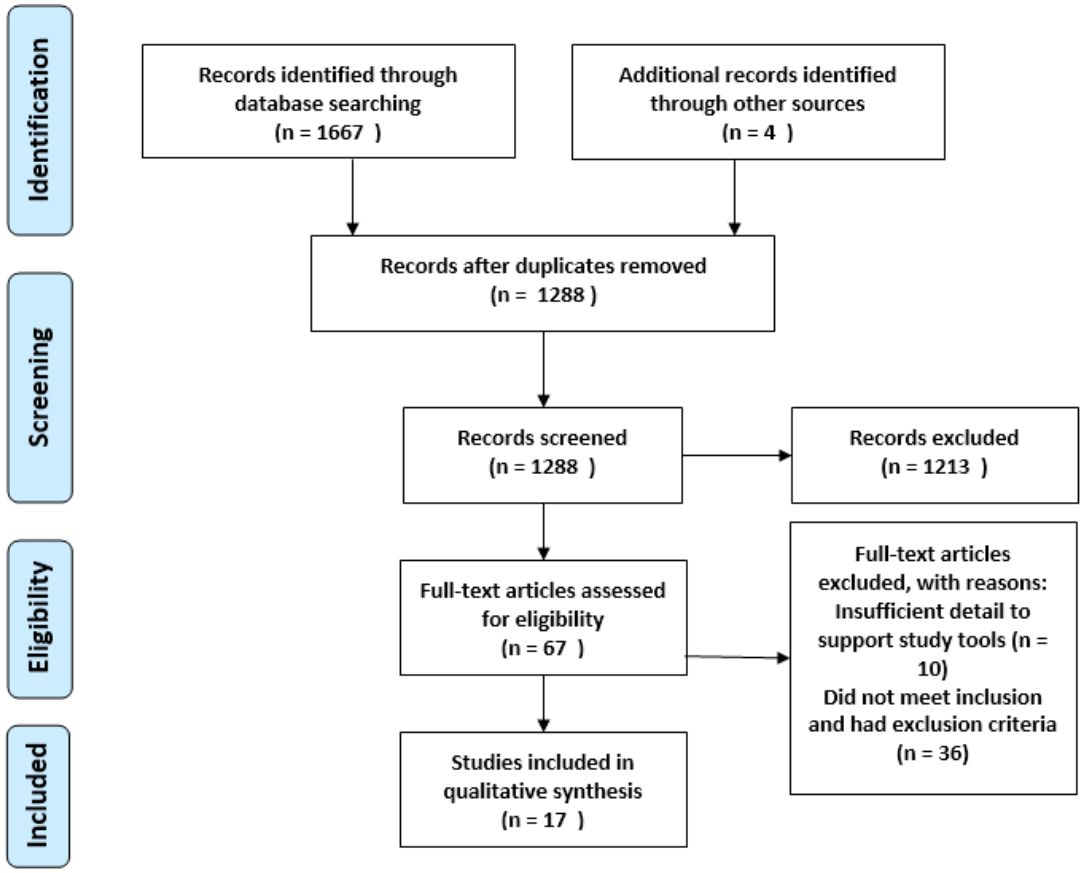
**Public and Patient Involvement**

A Bloodwise Patient Ambassador with CML was consulted about the project and study methods. This included appropriate ways to recruit participants; the content and presentation of participant paperwork and reviewing the content of the field work materials to ensure it was all readable and easy to understand. Advice provided included the use of social media and snowballing, as well as the best ways to contact patient support groups.

**Recruitment of Participants**

Interview participants were UCLH CML patients identified using the eligibility and exclusion criteria. Sampling was stratified according to age and distance to UCLH from their home postcode, potential participants were then selected randomly from each group and invited to participate by letter. Focus group participants were self-nominated following advertisement through Bloodwise, CML Support, CML UK. They were recruited if they met the eligibility criteria and did not meet the exclusion criteria. This group was intended to see how views of UCLH patients compared with those across the UK.

**Figure 1: PRISMA Flow Diagram**




**Interviews and Focus Groups**

Written consent was obtained from all participants before the completion of the questionnaire and the start of the interview or focus group. The questionnaire was then completed followed by the interview or focus group. A semi-structured topic guide was used for the interviews and focus groups. The focus groups were facilitated by the Principal Investigator. These discussions were audio recorded and then transcribed by a professional transcriber.

**Analysis of Results**

The interview and focus group transcripts were thematically analysed through the development of a coding frame using an inductive approach (Smith, 2010). Themes were established with collaborators Felicity Smith and Hiba Al-Robb (Supervisor and Clinical Lead). After discussions with Ian Bates (Supervisor), a matrix approach (Miles & Huberman, 1994) was used to identify any connections between demographic data and participants opinions and observational comparison of patient experience and opinions were made with national and UCLH NCPES results.

# Results

**Literature Review: Existing use of web-based video consultations**

The studies screened as part of the literature review included a wide range of conditions with different consultation models. However, they lacked detailed descriptions of these models and there were no specific examples of long term and continuous follow up of chronic conditions that also required specialised blood testing- details needed to inform the field work material and so were therefore excluded as per the criteria in Table 1. Despite being excluded, they do provide interesting insights as to the existing and past uses of web-based video consultations (see Table 2).

**Table 2: Summary of findings for the existing use of web-based consultations**

| Countries where studies took place | Conditions covered by the studies | Models of Consultation |
|---|---|---|
| • United States<br>• Canada<br>• Australia | • Mental Health<br>• Diabetes<br>• Parkinson's Disease<br>• Speech and Language Therapy<br>• Pain Management<br>• Post-Discharge of premature infants<br>• Post-surgery follow up | • Video calls for follow ups with no blood/lab tests required<br>• Patients undertaking video consultations from local hospitals with specialists in central hospitals +/- another HCP sitting with the patient<br>• Specialists consulting with non-specialist colleagues in remote areas |

**Questionnaire**

Table 3 summarises the responses to questions about participant demographics and provides insights into existing models of care and follow up for the participants. UCLH participants have blood tests, follow-up and collection of medicines all in one visit. Some of the focus groups participants used the same model, others highlighted different pathways with regards to blood tests and medicine delivery. This shows that there are a range of models in the existing care of CML patients.

None of the interview participants reported seeing a pharmacist as part of their follow-up, and only two focus group participants saw a pharmacist suggesting that pharmacists may have a limited role in the care of CML patients.

Table 4 summarises how the participants of this study score the NCPES questions compared to the national average score for patients with haematological cancers in 2018 (NCPES, 2018). These results show that the participants of this study could have received more information with regard to side effects and support groups. These questions scored lower compared to the national average for patients with haematological cancer patients. The written comments relating to their care echoed this with regards to improvements, however it was also clear from comments, that the care received was of a high standard and very much valued and appreciated:

**FOC_01:** *"There was no emotional support. I tried to look on the internet but found this disturbing."*

**FOC_03:** Improvement: *"Practical advice about personal support and life/side effect management early on"*

**FOC_03:** *"Very quick, decisions made w consultation rather than just being told e.g. dose reduction"*

**INT_01:** *"Kind, Professional, Expert"*

**Table 3: Participant Background and Current Follow-Up Appointment Routine**

| Question | Response | Interviews N = 5 | Focus Groups N= 8 |
|---|---|---|---|
| Age (Years) | 36-50 | | 3 |
| | 51-65 | 2 | 3 |
| | 66-74 | 2 | 2 |
| | ≥75 | 1 | |
| Time since initiating treatment (Years) | 1-2 | 2 | 2 |
| | 3-4 | 1 | 2 |
| | ≥ 5 | 2 | 4 |
| Healthcare Professionals seen at Follow-Up Appointments | Consultant Haematologist | 4 | 7 |
| | Nurse | 5 | 3 |
| | Pharmacist | 0 | 2 |
| | Other | 0 | 0 |
| Distance travelled for Follow Up Appointments (Miles) | 0-25 | 5 | 6 |
| | 26-50 | 0 | 2 |
| Time taken to travel to Follow Up Appointments (Minutes) | ≤ 30 | 1 | 3 |
| | 30-60 | 4 | 3 |
| | 61-90 | 0 | 1 |
| | 91-120 | 0 | 1 |
| Needed to book time off work for Follow Up Appointments | Yes | 1 | 2 |
| | No | 4 | 5 |
| Comes to appointments with someone else | Never | 3 | 6 |
| | Always | 1 | |
| | Sometimes | 1 | 2 |
| Frequency of Follow-Up Appointments | Every 2-3 months | 5 | 7 |
| | Every 4-6 months | | 1 |
| Timing and location of blood test | At the specialist centre before their appointment, on a different day | 5 | 3 |
| | At the specialist centre just before their appointment, on the same day | | 3 |
| | At the local hospital/clinic before their appointment, on a different day | | 2 |
| Medication Collection | Collect from the hospital where my follow up clinic is based | 5 | 5 |
| | Delivered to my home | | 3 |

**Table 4: NCPES Questions on Questionnaire**

| Question Text | Interviews N = 5 | Focus Groups N = 8 | Combined Interview & Focus Group Score N= 13 |
|---|---|---|---|
| Before your cancer treatment started, were your treatment options explained to you? | ↓ | ↑ | ↑ |
| Were the possible side effects of treatment(s) explained in a way you could understand? | ↓ | ↓ | ↓ |
| Were you offered practical advice and support in dealing with the side effects of your treatment(s)? | ↓ | ↓ | ↓ |
| Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away? | ↓ | ↓ | ↓ |
| Were you involved as much as you wanted to be in decisions about your care and treatment? | ↑ | ↑ | ↑ |
| Did hospital staff give you information about support or self-help groups for people with cancer? | ↓ | ↓ | ↓ |
| Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)? | ↓ | ↓ | ↓ |
| Did hospital staff give you information about how to get financial help or any benefits you might be entitled to? | ↓ | ↓ | ↓ |
| Did hospital staff tell you that you could get free prescriptions? | ↓ | ↓ | ↓ |

Key: ↑ = scored higher than the National Average in 2018; ↓= scored lower than the National Average in 2018 (NCPES, 2018)

**Interview and Focus Group Themes**

Eleven themes emerged from the thematic analysis of the transcripts, and can be split into themes relevant to the study objectives, and other emergent themes:

Themes Relevant to Objectives:

- Standards of Care
- Flexibility
- Continuity of the Team
- Remote vs Face-to-Face Consultations
- Alternative means of communication

Other emergent themes:

- Pharmacy Services
- Telephone vs Video Consultations
- Security Concerns
- Accessibility
- NHS Context
- Travel

**Standards of Care**

This theme focused on quality assurance of blood tests for both interview and focus group participants. It was clear they understood the sensitivity of the blood tests that were specific to their CML and they raised concerns that the result could be compromised if their bloods were taken away

from their specialist centre. Past experiences of shared care models where results had been lost were also raised.

**INT_05:** *"I'd prefer to have my bloods done at UCLH, and if you're interested in the reason it's because for me at the moment the most important test is the BCR-ABL, which is a highly specialised test"*

**FOC_02** *"…they lost my blood five times, so you have your blood and then you go for your follow-up appointment, oh there's no results because the blood was lost."*

**Flexibility:**

Focus group participants raised the option of having flexibility in follow-up models and when a face-to-face consultation vs a video consultation may be appropriate, for example, how stable they have been and also their stage of treatment.

**FOC_06:** *"specifically at the beginning of treatment ….. there's so many questions that you have, so I think at the beginning face-to-face is probably better, I didn't really care about distance or the cost, whatever, you just wanted to have that one-on-one contact, but now it's more of a routine……so now web consultation would be for me at least the best."*

**Continuity of the team:**

Focus group and interview participants valued the rapport and trust they had with their care team, and felt that this relationship would need to be established and maintained if remote video consultations were introduced.

**FOC_03:** *"I guess I'd be quite comfortable having a video consult with my doctor who I've known for years and see her every three months…… I've kind of built up the relationship, I know her well, I trust her"*

**Remote vs Face-to-Face Consultations:**

The discussion about the pros and cons of remote and face-to-face consultations gave some insights into what participants needed from follow-up appointments. Simplicity and practicalities were important, but also how different models could meet different the emotional needs.

**INT_01:** *"for me both of those* [remote models] *would be worse, they involve far more steps, far more meetings, far more events, so I would prefer to remain as it is."*

**FOC_08**: *"I've found it quite scary going into the hospital environment at the beginning….. I think a video conference would have been good for me"*

**FOC_03:** *"I find the clinic environment quite sort of comforting and reassuring, and a safe place"*

The participants also discussed the benefits of remote consultations for society as a whole.

**INT_07:** *"I'm more old school and prefer to have one-on-one dialogue. But I wouldn't be against a web based consultation if it would benefit the entire system. I think a web based consultation would be perfectly acceptable, but only if the efficiencies are generated"*

**FOC_01:** *"I mean from a cost point of view, I mean that has occurred to me…… money could be saved by not having a consultant in a clinic ….. And possibly save some time, so and obviously if that was a decision made then I would be very happy to go along with the web based consultation."*

**Alternative means of Communication**

The type of information different focus group participants received from their team also varied. This again highlights the differences in models of care for CML patients.

**FOC_03 "***I've never had any letters…. what do you get letters with your test results do you? Oh right, no, all I get is a copy of the letter that the consultant sends to the GP. But it hasn't got any results on it actually…..it just says that I'm doing well so [laughs]…."*

# Discussion

Overall the results obtained have allowed the aim and objectives of the study to be met. Web-based video consultations are being used in a range of health related areas, however many were reports of small pilot studies and may highlight the need for larger and longitudinal studies to be carried out in this area. Possible remote models of care were proposed to interview and focus group participants and their opinions about these, what their care needs are and their current care models were also established to help identify what their acceptability of web-based consultations models would be, and the factors that would influence this.

**Acceptability of web-based video consultations**

Within the focus groups, there were mixed preferences for web-based video consultations and for the UCLH participants they would all prefer to continue having face-to-face follow ups. However, participants across both groups would be accepting of video consultations if it benefited the NHS and provided efficiencies that would benefit everyone.

Participants also shared what was important to them as patients and what would make remote web-based video consultations more acceptable to them. These key considerations are summarised in Table 5 and maybe useful to guide organisations who are considering introducing such a service and need to create protocols and policies.

**Patient Satisfaction with existing care**

Given the small number of participants a statistical comparison cannot be made comparing the participant responses to the NCPES questions with national results. However, it may indicate that more work needs to be done in this area to investigate whether this is something related to CML patients or particular groups of haematology patients. Overall participants, have had a positive patient experience in the management of their CML but they could have benefitted from more advice on side effects and support groups. The role of pharmacists in the care of this group of patients is

varied so further work could be carried out to explore how pharmacists can be further integrated into the care of CML and similar patients, perhaps in relation to the provision of advice about side effects.

**Table 5: Recommended factors for consideration when introducing web-based consultation models**

| Factor |
| --- |
| • The importance of an established rapport and trust with patients before introducing video consultations |
| • Stage of diagnosis and treatment- maybe less suitable early in treatment after change in treatment |
| • Should not replace all face-to-face contact |
| • Flexibility in the service to allow face-to-face contact if needed |
| • Reliability of any test results that may be carried out remotely |
| • Reliability and security of remote medicine supply |
| • Adequate security and environment for consultations to take place |
| • The consultation pathway should not get more complicated compared to the current pathway |

**Limitations**

Challenges in recruiting interview participants has been a limiting factor in this study. The views of five patients may not be representative of all CML patients at UCLH. This has prevented reliable statistical analysis and comparisons to be made between interview and focus group participants. Interview participants all live within 25 miles of UCLH, and the Focus Group participants live in places with a straightforward train journey to London, meaning the views of those in more rural geographies may not be represented. However, the qualitative aspect of the study has allowed exploration in greater depth to inform future studies in this area.

# Impact

The key considerations highlighted in Table 5 could be used to inform local decisions and policy at UCLH, or on a wider level across London and nationally- not just in CML patients but in patients who have chronic conditions with long term follow up in specialist centres. The findings of this study can also be used as a basis for potential future work, including the development of a questionnaire that explores acceptability of web-based video consultations. This could be sent to a wider population e.g. other haematology patients, or patients with long term chronic conditions.

# Dissemination

**Dissemination Activities Undertaken**

- **October 2019:** Presentation of the BOPA Research Grant Results (2017 Award) at the International Society of Oncology Pharmacy Practitioners and BOPA Symposium.

**Planned Dissemination Activities**

- Presentation at Health Services Research and Pharmacy Practice (HSRPP) Conference in Cardiff 2020, and London Cancer Chemotherapy Expert Reference Group
- Publication of open access journal article
- Plan to produce a summary of key findings, written in plain English for interested parties including participants, Bloodwise Ambassadors, CML Support UK, CML UK Support group

# Conclusion

Certain considerations need to be taken before introducing web-based video consultation services. Whilst some participants would prefer face-to-face consultations, they would be accepting of video consultations to help ease NHS pressures.

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