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Developing and evaluating the use of telemedicine in CADASIL

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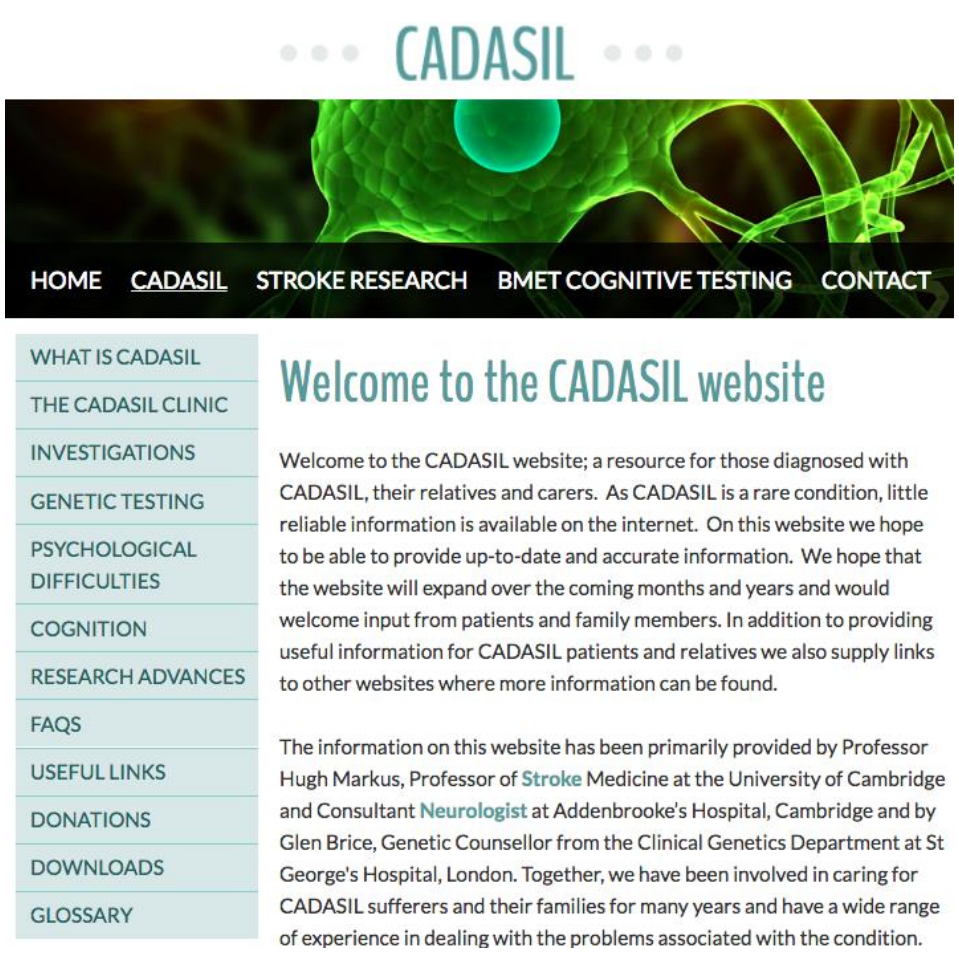
What is telemedicine?

- Telemedicine is any form of technology used for the treatment of patients
- Used to reduce travel times and costs to patients
- We trialed the use of Skype in our CADASIL clinic at Addenbrooke's hospital for follow-up consultations

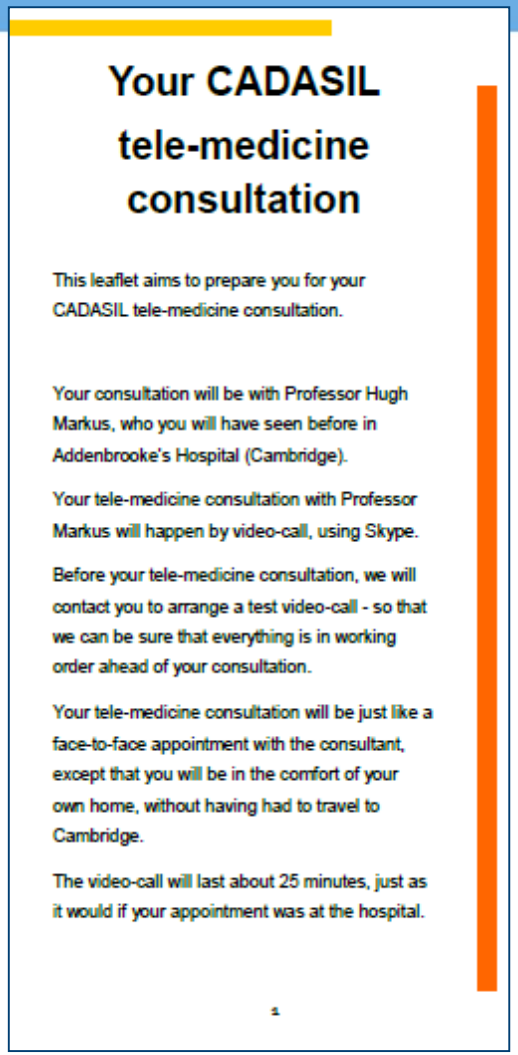
Why is it useful for the CADASIL clinic?

- Our CADASIL clinic is national
- Many of our patients have to travel long distances to access the specialist care
- This comes at a great time and monetary cost to the patients
- We wanted to find a way to reduce the burden of this cost and make appointments more accessible



How does telemedicine work?

- Telemedicine appointments are offered for all follow-up consultations
- Information pack sent out explaining how to set up Skype
- Contact information for if you have problems
- Practice call organised to check sound and video are working
- Consultation with Professor Markus over Skype



Your CADASIL tele-medicine consultation

This leaflet aims to prepare you for your CADASIL tele-medicine consultation.

Your consultation will be with Professor Hugh Markus, who you will have seen before in Addenbrooke's Hospital (Cambridge).

Your tele-medicine consultation with Professor Markus will happen by video-call, using Skype.

Before your tele-medicine consultation, we will contact you to arrange a test video-call - so that we can be sure that everything is in working order ahead of your consultation.

Your tele-medicine consultation will be just like a face-to-face appointment with the consultant, except that you will be in the comfort of your own home, without having had to travel to Cambridge.

The video-call will last about 25 minutes, just as it would if your appointment was at the hospital.

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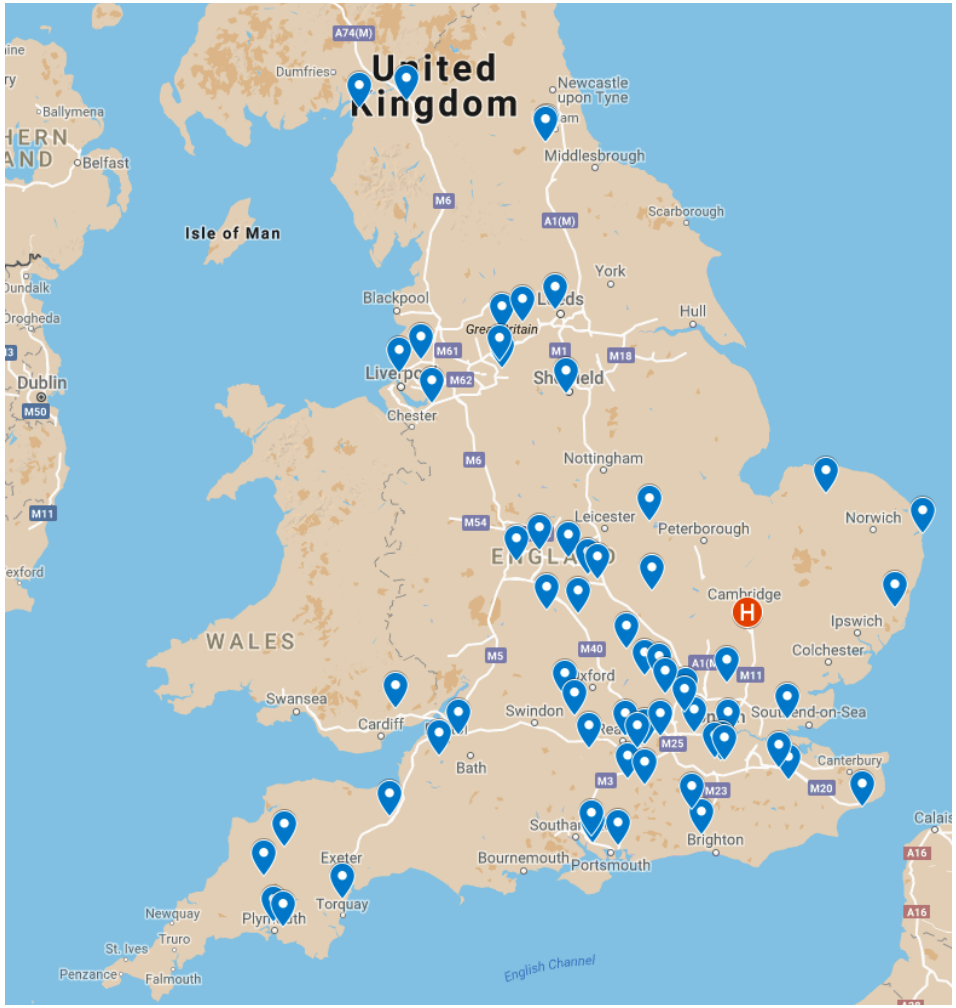
Evaluation

- We evaluated 64 first time telemedicine appointments and 50 face-to-face appointments
- We evaluated 26 second time telemedicine appointments and 3 third time appointments
- All participants had a diagnosis of CADASIL



Methods: Patient questionnaires

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EVALUATION DOCUMENT A

Please mark the correct answers with an X

Do you have any difficulties with vision? Yes ☐ No ☐

Do you have any difficulties with hearing? Yes ☐ No ☐

Do you have any difficulties with speech? Yes ☐ No ☐

Was someone present with you during your consultation? Yes ☐ No ☐

If yes, please state who (e.g. partner, carer) _____

Have you had a stroke? Yes ☐ No ☐ If yes, when/ how long ago? _____

Do you have any cognitive (thinking/understanding/memory) problems that you are aware of?

Yes ☐ No ☐ If yes, please briefly describe:

_____

Did you feel well today? Yes ☐ No ☐ If no, what was wrong? :

_____

Please mark with an X the response that best matches your answer to the statement given

	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
I could talk to the doctor easily and openly					
I felt I could ask my doctor questions					
I did not feel that anything important was missed during my appointment with my doctor					
I understood what the doctor told me					
I felt that the doctor answered all of my questions and concerns					
I felt that the doctor was able to understand my situation and provide satisfactory care					
I felt my privacy and confidentiality were preserved during my appointment with my doctor					

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Tele-med ☐ Face-to-face ☐

Participant ID_____ Consultation date_____

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	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
I was able to develop a friendly relationship with my doctor					
I feel comfortable discussing sensitive things about my illness with my doctor					
I felt that my welfare was important to the doctor					
The doctor considered my opinions and comments when planning the next course of action for my care					
There was enough time to discuss everything that needed discussing					
I had no difficulty seeing or hearing the doctor through the video-call system					
The equipment was easy to use					
I am getting satisfactory care from the doctor via tele-medicine					
For future appointments, I would rather travel to Cambridge than have another tele-consultation					
A tele-consultation is just as good as going to the out-patient clinic to see the doctor					
Any problems with today's consultation or any suggestions for improvement?					

Would you like your next follow-up appointment at the CADASIL clinic to be via tele-medicine?

Yes ☐ No ☐

How would you have travelled to Cambridge today if you had a face-to-face consultation? :

_____

Would you or someone else have been responsible for paying for this journey? :

_____

Please make sure that you have answered all the questions, thank you.

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Tele-med ☐ Face-to-face ☐

Participant ID_____ Consultation date_____

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Methods: Patient questionnaires

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EVALUATION DOCUMENT B

Read each item and circle the reply which comes closest to how you have been feeling in the ***past week***. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response. *Please make sure that you have answered all the questions and complete the questionnaire within one week of your consultation, thank you.*

I feel tense or 'wound up':		**I feel as if I am slowed down:**	
Most of the time	3	Nearly all of the time	3
A lot of the time	2	Very often	2
Time to time, occasionally	1	Sometimes	1
Not at all	0	Not at all	0
I still enjoy the things I used to enjoy:		**I get a sort of frightened feeling like 'butterflies in the stomach':**	
Definitely as much	0	Not at all	0
Not quite so much	1	Occasionally	1
Only a little	2	Quite often	2
Not at all	3	Very often	3
I get a sort of frightened feeling like something awful is about to happen:		**I have lost interest in my appearance:**	
Very definitely and quite badly	3	Definitely	3
Yes, but not too badly	2	I don't take as much care as I should	2
A little, but it doesn't worry me	1	I may not take quite as much care	1
Not at all	0	I take just as much care as ever	0
I can laugh and see the funny side of things:		**I feel restless as if I have to be on the move:**	
As much as I always could	0	Very much indeed	3
Not quite so much now	1	Quite a lot	2
Definitely not so much now	2	Not very much	1
Not at all	3	Not at all	0
Worrying thoughts go through my mind:		**I look forward with enjoyment to things:**	
A great deal of the time	3	As much as I ever did	0
A lot of the time	2	Rather less than I used to	1
From time to time but not too often	1	Definitely less than I used to	2
Only occasionally	0	Hardly at all	3
I feel cheerful:		**I get sudden feelings of panic:**	
Not at all	3	Very often indeed	3
Not often	2	Quite often	2
Sometimes	1	Not very often	1
Most of the time	0	Not at all	0
I can sit at ease and feel relaxed:		**I can enjoy a good book or radio or TV programme:**	
Definitely	0	Often	0
Usually	1	Sometimes	1
Not often	2	Not often	2
Not at all	3	Very seldom	3

Tele-med ☐ Face-to-face ☐

*Participant ID*_____ *Consultation date*_____

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EVALUATION DOCUMENT C

This questionnaire needs to be completed as soon as possible, following your consultation.

This questionnaire is about how you feel ***right now***. Read each statement and then mark with an **X** the box with the most appropriate answer to indicate ***how you feel right now, at this moment***.

There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately	Very much
I feel calm				
I am tense				
I feel upset				
I am relaxed				
I feel content				
I am worried				

Please make sure that you have answered all the questions, thank you.

Tele-med ☐ Face-to-face ☐

*Participant ID*_____ *Consultation date*_____

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Methods: Clinician questionnaire

Cambridge University Hospitals NHS

Clinician satisfaction questionnaire

Please mark with an X the response that best matches your answer to the statement given

	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
I was able to identify the real concern(s) of this patient/family					
I could build rapport with the patient					
I felt confident at the end of the consultation that everyone was *on the same page*					
I felt confident at the end of the consultation that the patient was feeling satisfied by the consultation					
I felt confident in treating this patient's problems using tele-medicine equipment					
I was able to present the same information I would have presented in person					
The tele-medicine equipment worked well today					
The tele-medicine consult did not cause me extra work					

1

Tele-med ☐ Face-to-face ☐

*Participant ID*_____ *Consultation date*_____

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Other comments/concerns:	
How many minutes-long was the consultation?	

Does the patient have a clinical diagnosis of dementia? Yes ☐ No ☐

Modified Rankin Scale (0-6) (see below, if required): _____

Are you happy for your next follow-up appointment with this patient to be via tele-medicine?

Yes ☐ No ☐

Please ensure that you have answered all the questions.

MRS

0	No symptoms at all
1	No significant disability despite symptoms; able to carry out all usual duties and activities
2	Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3	Moderate disability; requiring some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
6	Dead

2

Tele-med ☐ Face-to-face ☐

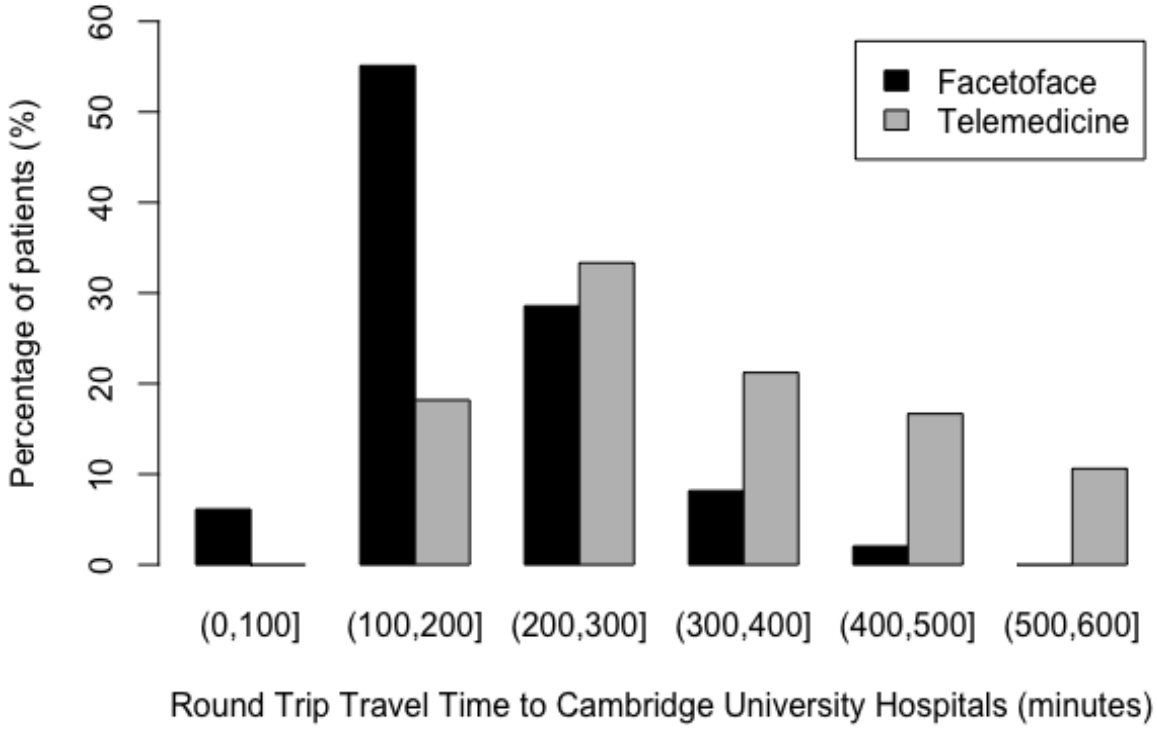
*Participant ID*_____ *Consultation date*_____

Results: Demographics

	Face-to-face	Telemedicine	P value
Age (>=60 years old)	38% (19/50)	27% (17/64)	0.7389
Disability (MRS>=3)	22% (11/50)	20% (13/64)	0.6831
History of stroke (self-reported)	42% (20/48)	34% (19/56)	0.8728
Visual difficulties (self-reported)	29% (14/48)	18% (10/56)	0.4142
Hearing difficulties (self-reported)	17% (8/48)	13% (7/56)	0.7963
Speech difficulties (self-reported)	15% (7/48)	18% (10/56)	0.4669
Cognitive problems (self-reported)	44% (21/48)	43% (24/56)	0.6547
Clinical dementia (clinician-reported)	16% (8/50)	20% (13/64)	0.2752

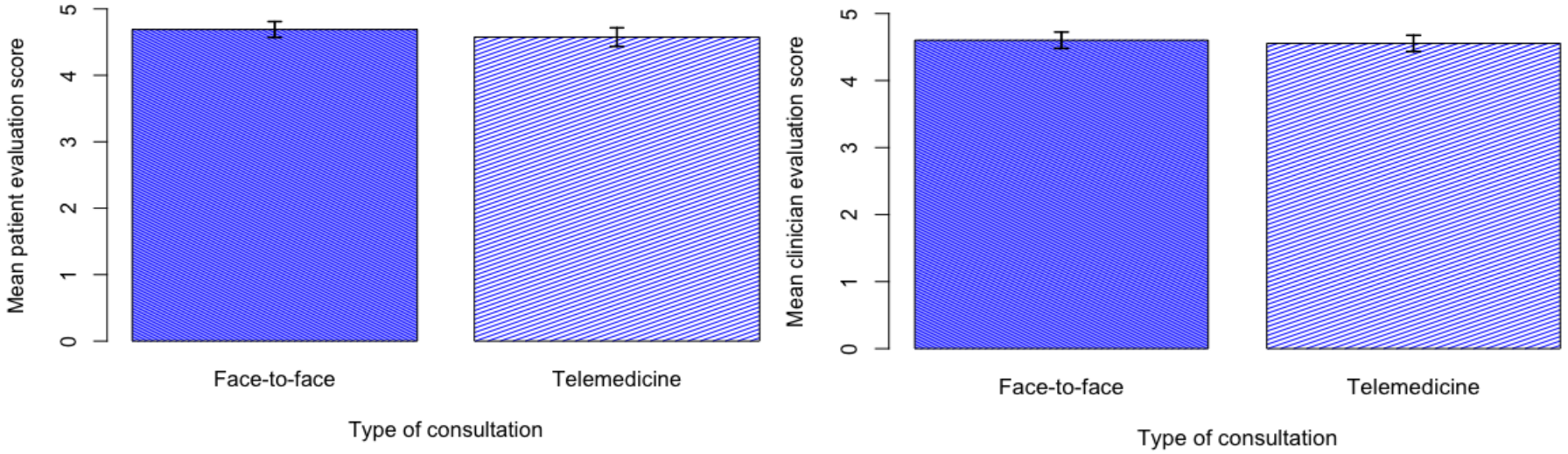
Results: Distance from Addenbrooke's Hospital

- Patients who chose to use the telemedicine service lived significantly further away from the hospital



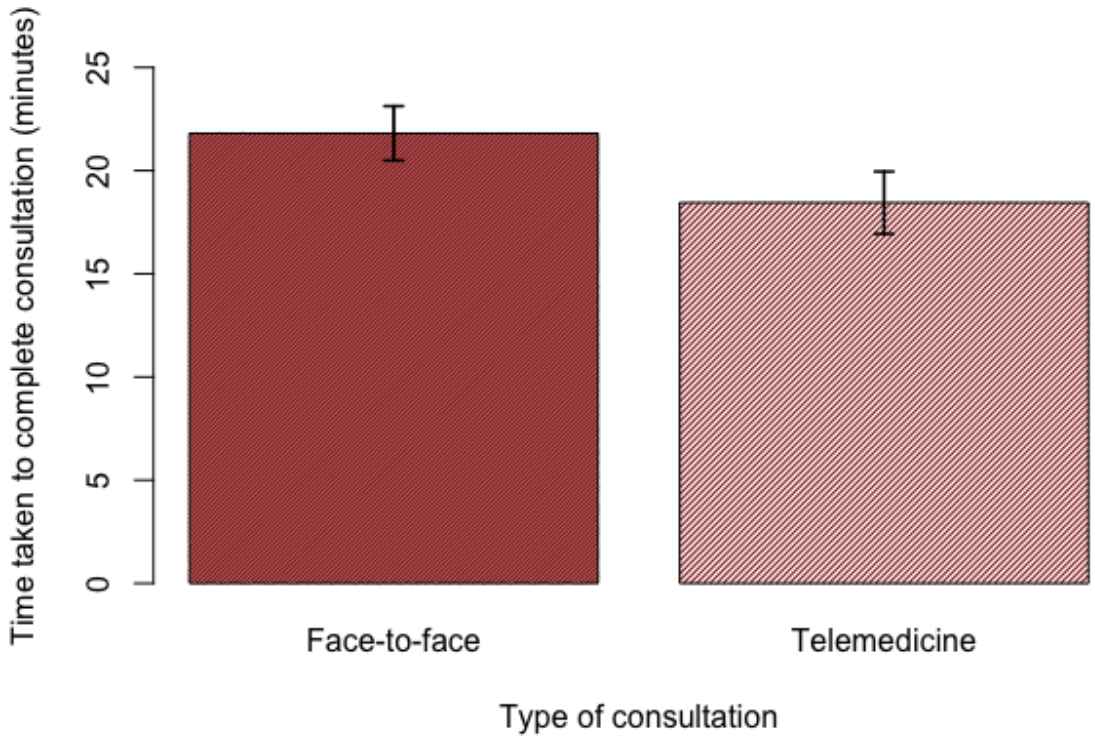
Results: Evaluation

- Evaluation scores from patient and clinician were no different in telemedicine compared to face-to-face



Results: Time Taken

- Telemedicine consultations took a significantly shorter time than face-to-face consultations, suggesting they could save the NHS money



Results: Anxiety and Depression Scores

- Anxiety and depression scores were the same for both types of consultations suggesting that telemedicine consultations do not cause extra anxiety for the patients

	Face-to-face	Telemedicine	P value
HADS Anxiety	6.25 (4.6)	7.28 (4.9)	0.33
HADS Depression	3.93 (3.7)	5.61 (5.1)	0.18
STAI-6	34.51 (14.9)	37.55 (13.6)	0.15

Results: Cognitive Problems

- Patients with self-reported cognitive problems had lower satisfaction scores overall for both telemedicine and face-to-face consultations

Appointment type	Cognitive problems	No cognitive problems	P value
Face-to-face	4.48(0.43)	4.85(0.34)	<0.001
Telemedicine	4.22(0.63)	4.79(0.35)	<0.001

Would patients use our telemedicine service again?

- 93% of patients who used the service said that they would like their next follow-up appointment to be via telemedicine

What feedback have we had from users?

- ‘Telemedicine session was ideal, timely, professional and absolutely the way forward.’
- ‘This system is brilliant, saved me 6 hours travelling time.’
- ‘Perfect approach and use of tech. Saved 12 hour journey.’
- ‘It was excellent. Far preferable to travelling to Cambridge.’

Conclusions

- Our telemedicine service was shown to be successfully received by patients and clinician
- The service was shown to shorten consultation times so could be beneficial and cost-saving for the NHS
- The service has now been implemented as part of routine care with Kate Rose responsible for it

Would you like to use telemedicine for your follow-up appointment with Professor Markus?

Let Kate know when she calls you to book you in for your next follow-up appointment!

Thank you!

- All patients who evaluated their appointments for us

- Kate Rose
- Hugh Markus

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Any questions?