A new, integrated, opt-out model to connect patients with clinical research opportunities

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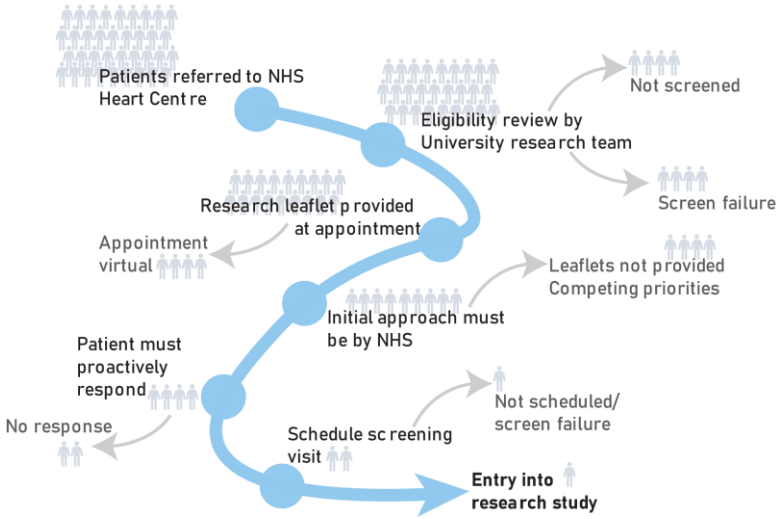
Our patients tell us that they want to take part in clinical research studies. However, even in Academic Health Science Centres, the enrollment process is cumbersome and organizational silos frequently hinder participation. The aim of this project is to investigate the feasibility of developing a new opt-out model to connect researchers and patients more directly. The proposed model will streamline connections between patients, clinicians and researchers whilst maintaining the highest standard of ethical compliance.

OBJECTIVES

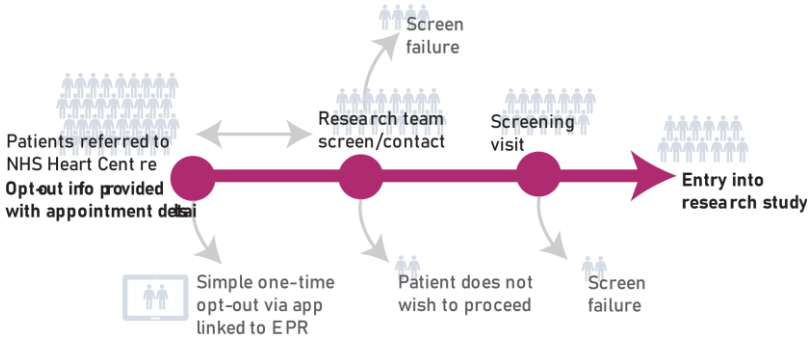
- To design a new model for research initially in the Heart Centre, but with potential to scale across the organization
- To identify and engage key stakeholders across both organizations as well as patients
- To develop a strategy for software support/EPR integration
- To implement a proof-of-concept pilot in a local University imaging department and stress-test the concept before wider roll-out

Current model: A LEAKY PIPELINE THAT INHIBITS RESEARCH



- × Complex, multistep process with frequent attrition of suitable patients who want to take part
- × Virtual appointments not easily accommodated
- × Fewer patients connected with research studies

Proposed solution: A STREAMLINED OPT-OUT MODEL



- ✓ Streamlined process to connect eligible patients with suitable research studies
- ✓ Mitigation of organizational siloes
- ✓ Simple opt-out mechanism recorded in EPR
- ✓ Clear ethical guardrails

PROGRESS AND LESSONS LEARNED

- ✓ Key stakeholders in University and NHS identified and engaged
- ✓ Ethical guardrails defined
- ✓ Patient and public involvement in project initiated
- ✓ Strategy for future EPR integration identified – resource to deliver EPR functionality lacking and likely to be rate limiting
- ✓ Pilot model established and running (without EPR integration yet) in a University department

CONCLUSIONS

- There is broad consensus that current legacy system is not working well and can be improved
- Key stakeholders have been identified and engaged
- A proof-of-concept study is underway in a single University Department
- The current barrier is that EPR is not configured to allow patient access and 3rd party solution is not funded → work ongoing
- Further work will continue to develop this process

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