

# Partnerships with patients and the public

## Putting research at the heart of healthcare

**Promoting, conducting and using clinical research to improve healthcare is one of the key principles of the NHS making a positive difference to patients health within Scotland, the UK and internationally.**

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### AIM

Continuing to create value for patients and the NHS from clinical trials conducted in Scotland can only be achieved with greater participation. To increase participation, NRS and SHARE work collaboratively to:

- Promote greater awareness of research and clinical trials to the public
- Ensure every patient is given the opportunity to take part in a clinical trial if they wish, providing access to innovative medical advances and cutting-edge treatments
- Empower patients to become actively involved in all aspects of clinical research
- Demonstrate the value of research within our NHS.



### METHODS

NHS Research Scotland has worked to establish a strong research infrastructure that ensures the successful delivery of well-designed, scientifically valid research which also incorporate the insights and views of patients, carers and relatives and provides opportunities for involvement in all aspects of research.

- The establishment of SHARE – an NHS Research Scotland initiative to create a register of people interested in participating in health research
- Support of International Clinical Trials Day and key awareness days that expand public knowledge of clinical trials and enhance engagement with research charities, patient advocate groups and wider public
- Established Topic Networks and Speciality Groups across all disease areas to support clinical research in Scotland and act as the interface between NHS Scotland, the research community, charities and the public
- Encourage patient and public involvement (PPI) in research to improve the governance and quality of clinical trials undertaken in Scotland.



*“The Scottish public are at the heart of clinical research, both as healthy volunteers participating in early stage studies and as patients benefiting from improved diagnoses or treatments. Without patients enrolling to take part in clinical research, very little of the research conducted in the NHS would be possible.”*

*Delivering Innovation through Research, Scottish Government Health and Social Care Research Strategy, October 2015, p.19*

### OUTCOMES/RESULTS

- During 2015/16, over 1000 clinical research studies took place in Scotland, with over 37,000 patients participating.
- Over 159,000 members of the public have registered with SHARE (April 2017) to participate in future research
- Positive collaboration with a range of research charities, including joint delivery of trials and studies, investment in research facilities, or funding research fellowships to advance understanding and treatment of key diseases, supports ground-breaking research in Scotland and across the UK
- Regular public involvement with events to engage patients in research including:
  - Cardiology Research Day, bringing together patients and researchers to talk about clinical trials and next steps
  - Regular meetings for members of the public to give practical and constructive feedback on research projects taking place in Primary Care (GPs or dentists)
  - Memory research awareness event to discuss research in neurodegenerative disease
  - Participation of patients in events as speakers and chairs.



### CONCLUSION

Without the agreement of patients to take part, very little of the research conducted in the NHS would be possible. New medical treatments and therapies are being developed through research all the time, bringing hope to people living with illness.

### REFERENCES

[www.nrs.org.uk](http://www.nrs.org.uk)

[www.registerforshare.org/](http://www.registerforshare.org/)

Scottish Government, Delivering Innovation through Research,  
Scottish Government Health and Social Care Research Strategy, October 2015  
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