



Recruiting for Research, Improving our Health

Research in Scotland

Medical research in the UK is a success story!

- Funding ✓
- Publications ✓
- University standing ✓
- Novel drugs, treatments, service improvements ✓



We could do better!



- Threats:
 - The costs of research are rising
 - Research has shifted to developing nations
- We need to be more efficient
 - Improve recruitment
 - Capitalise on existing infrastructure
 - Superb NHS
 - World beating health datasets



Why SHARE is needed

- Recruitment to UK studies often fails
 - loss of confidence of the pharmaceutical industry, and a reduction in commercial studies.
 - Requests for further funding from academic studies in order to complete.
 - Not cost-effective and potentially unethical

Why do studies fail to recruit?

- Difficulty identifying willing participants
 - Fewer patients staying in hospitals
 - Only the very ill attending OPD
 - 90% of NHS activity in primary care
- Getting GP practices on board
 - Accessing busy GPs/PNs to explain studies
 - Searching GP records
 - Relatively small numbers in each practice



The problem

- Researchers cannot contact potentially interested participants
- Potentially interested patients are unaware of studies



That's why we invented



Recruiting for Research, Improving our Health

What is SHARE?

- A register of people aged 16 or over and living in Scotland who have said they are interested in helping with medical research. With permission to link to their NHS Datasets to establish their eligibility for research projects.
- Builds upon Scotland's excellent informatics
 - Databases
 - Record Linkage

CHI	DOB	PostCode	Date	ContactPref	AnnualNo
0707551536	19550707	PH26QB	20120604	Post	4

The screenshot shows the NHS Scotland website. The header includes the NHS Scotland logo and navigation links: HOME, NEWS, CALENDAR, CONTACT, and CONNE. Below the header, there are icons for 'FOR THE INDUSTRY' and 'FOR'. A blue navigation bar contains links: ABOUT NRS, INFRASTRUCTURE & ASSETS, NRS NODES, PERMISSIONS COORDINATING CENTRE, and FOR. Below this, a breadcrumb trail reads 'YOU ARE HERE:'. The main content area features a news article with the headline 'NEW CENTRES PUT HEALTH RECORDS AT THE HEART OF UK MEDICAL RESEARCH'. The article text states: 'A consortium of 10 UK government and charity funders, led by the Medical Research Council (MRC), has made a historic £19 million investment to establish four e-health research Centres of Excellence in London, Manchester, Dundee and Swansea. The funding awards were announced today at the British Business Embassy's life sciences summit at Lancaster House by the Minister for Universities and Science David Willetts. The Centres will open in late 2012 and will harness the wealth of UK electronic health records to improve patient care and public health.'

What do people think of this?

- Patients were very supportive about the SHARE idea
 - Embedding within the NHS was particularly reassuring
 - Confidentiality paramount
- Researchers were enthusiastic and could see many advantages
 - Concerns about governance and ease of access
- GPs and PMs supportive in principal
 - Concerns about data protection and workload

Grant A, Ure J, Nicolson D, Hanley J, Sheikh A, McKinstry B, Sullivan F. Acceptability and perceived barriers and facilitators to creating a national research register to enable 'direct to patient' enrolment into research: the Scottish Health Research Register (SHARE). BMC Health Services Research (in press)

Research and regulatory bodies

- Ethical approval granted
- Caldecott guardian approval granted
- BMA supportive as participation by patients is consented
- Charities and Pharma keen to see a register but unwilling to fund its development.
- Funding bodies see use of SHARE as a reasonable charge in grants.



SAVE LIVES

Sign up now.

It takes less than a minute to submit your details

REGISTER

TELL YOUR FRIENDS

 Like 259  Tweet

SHARE YOUR STORY



WATCH THE VIDEO



1 0 0 0 0 0

People registered so far



ANY QUESTIONS?






WHAT'S NEW?

SHARE assists on the biggest s... //
SHARE has started 2016 in grand style having assisted on the largest study to date, with nearly 50,000 people from the SHARE register being invited to participate through email.... [Read More](#)

SHARE now over 90,000 registra... //
The SHARE register continues to grow with

WHAT IS SHARE?

SHARE is a new NHS Research Scotland initiative created to establish a register of people interested in participating in health research and who agree to allow SHARE to use the coded data in their various NHS computer records to check whether they might be suitable for health research studies. This access can be incredibly useful when it comes to developing new treatments and cures for a wide variety of health conditions.

-  Improve future healthcare in Scotland
-  Research can lead to better treatments and cures for you and your family
-  Just sharing your details is enough to help
-  Option to participate in health trials if you want
-  It's easy to sign up or opt out



YOU ARE HERE: HOME / RESEARCHERS

RESEARCHERS

Information about SHARE for researchers

1... [Feasibility request form for researchers can be downloaded here](#)

2... [The application form for researchers can be downloaded here.](#)

3... [The GoSHARE Collaboration form for researchers can be downloaded here.](#)

Please complete the application form and email it to Margaret McCann at M.Z.McCann@dundee.ac.uk along with ethics approval, protocol and PIL.

If you are a researcher interested in discovering more about SHARE, becoming registered and gaining access to health records for your research projects, you will find some useful information below.

SHARE introduces costs for studies

If submitting a research application then please be aware then there may be a cost recovery for utilising SHARE resources. This will be discussed on receipt of research application.

SAVE L

Sign up n

It takes less than a minute to

REGIST



Application no:
SHARE_



Recruiting for Research, Improving our Health

SHARE Application Form

Important Please Note: Please complete ALL fields.		
Project Working Title/Acronym:		
Do you have NHS ethics and R&D approval for eligible subjects using the SHARE register for this study?	Yes <input type="checkbox"/>	No <input type="checkbox"/> Please state R&D number: Please include a copy of ethics and R&D approval letters as well as your Protocol and PIL as an appendix
How many participants do you hope to recruit from SHARE?		
Which NRS nodes do you plan to recruit from?	All /North /East/Southeast/West	
Duration of study	Start date:	End date:
Type of study:	Recruitment <input type="checkbox"/> Other <input type="checkbox"/>	

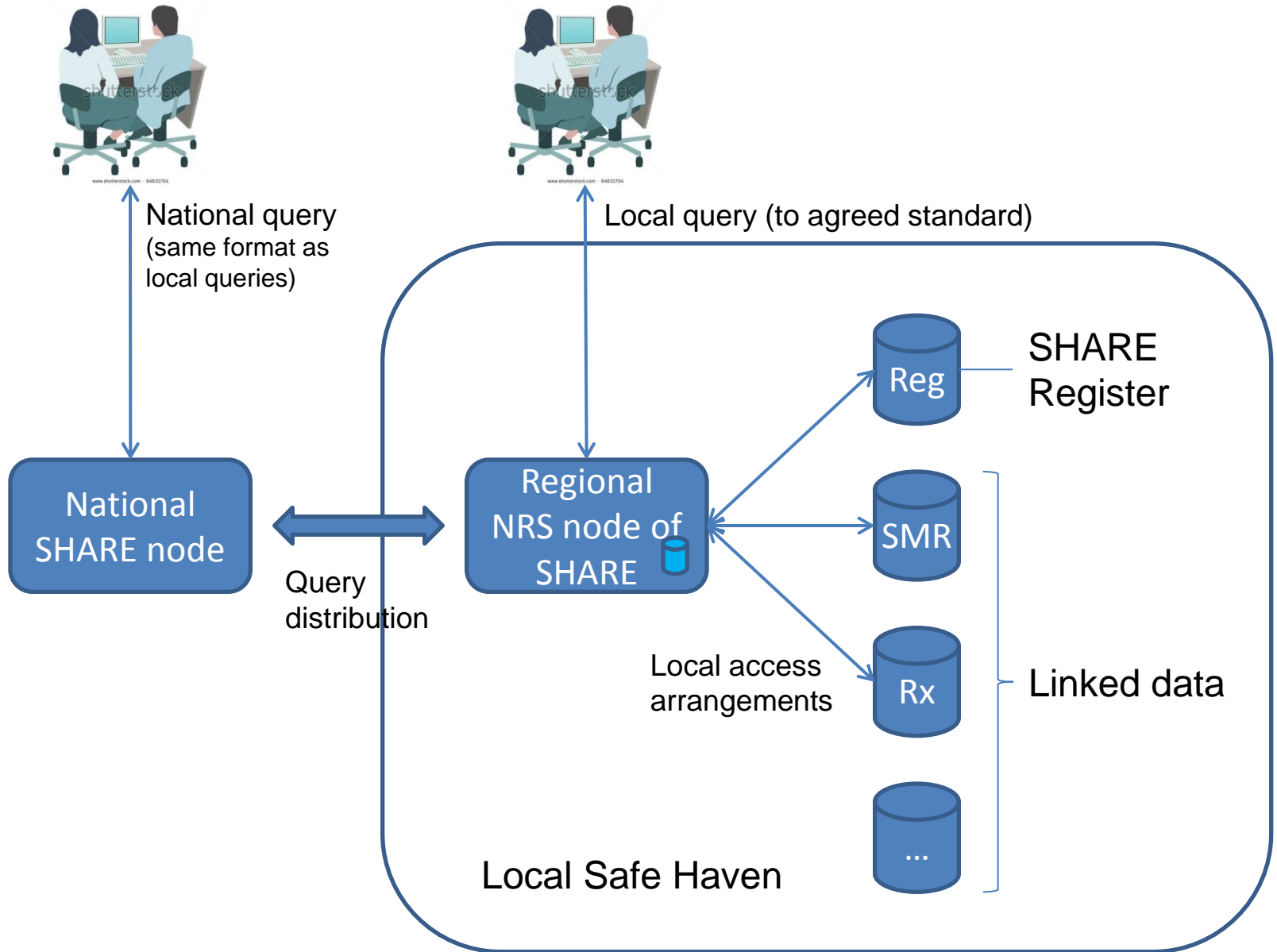
Study Co-ordinator Details:	
Title/Full Name:	
Address:	
Postcode:	
Daytime Telephone Number:	
Email:	
Chief Investigator Details:	
Title/Full Name:	
Address:	
Postcode:	
Daytime Telephone Number:	
Email:	
Local PI (s):	

What to send SHARE

- Completed and signed application form
- Current protocol with SHARE listed as source of recruitment
- R&D Approval
- Ethics approval
- Participant information Leaflet
- National committee decides if feasible
- Pricing structure under review
 - Fee per contact (postage and handling)
 - Fee per successful recruit.



Local but National



- If it looks someone is a good fit.
The SHARE contacts them and lets them know about the research and ...if they are interested puts them in touch with the research team.
- If they don't feel like feel like helping this time they just say no.
- SHARE participants can choose how often they are contacted

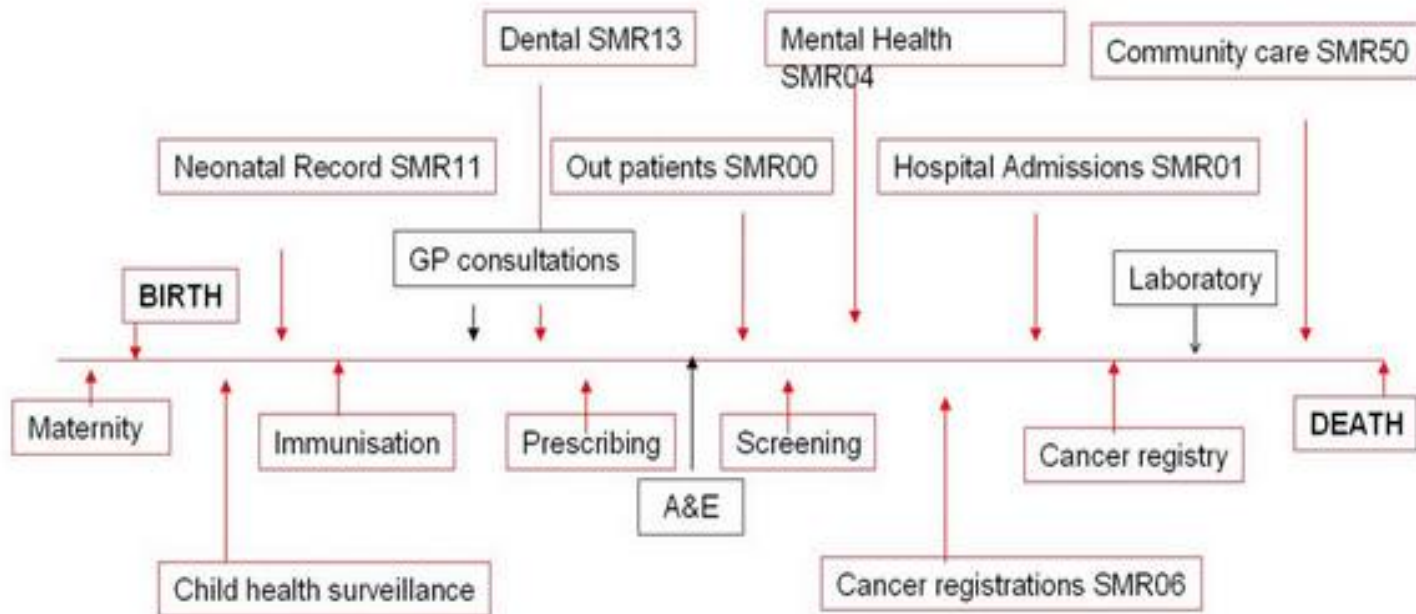




What will SHARE Deliver ?

- List of individuals who fitting eligibility criteria, and willing to participate having heard about the study.
- We will supply researchers with contact information including best time and number to get in touch.

Scottish Health Datasets



Research datasets available

- Currently we are using mainly discharge diagnostic data and prescribing data
- Gradually start to increase the data sources we are using
- Centralisation of data in the Farr institute particularly GP data offers opportunities
 - Not yet clear how that interaction will take place probably safe havens.

How sick is the SHARE population?

Medication	Scotland		Condition	Scotland
Analgesics	29494		Any malignancy	4970
Anti-Diabetic Drugs	6699		Cerebrovascular disease	2166
Antidepressant	19390		Chronic pulmonary disease	4903
Antihypertensives	23710		Congestive heart failure	1268
Cardiovascular System	36292		Dementia	141
Central Nervous System	40550		Diabetes with chronic complication	407
Endocrine System	22612		Diabetes without chronic complication	5155
Gastro-Intestinal System	48832		Hemiplegia or paraplegia	354
Infections	34808		Metastatic solid tumor	969
Inhaled Steroids	7670		Mild liver disease	1000
Lipid Modifying Drugs	19009		Moderate or severe liver disease	290
Musculoskeletal And Joint Disease	25058		Myocardial infarction	2509
NSAIDs including Cox-2	16572		Peptic ulcer disease	1197
Respiratory System	21216		Peripheral vascular disease	1537
Skin	28329		Renal disease	1718
Topical Steroids	17556		Rheumatic disease	1092

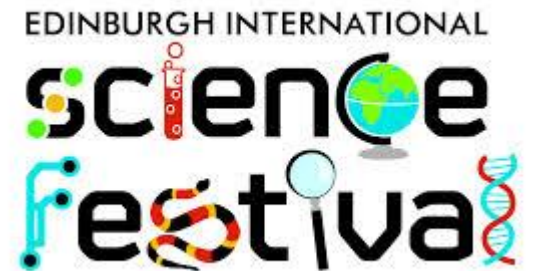
Age Demographics.

Age Range	Number of Registrations	Total - Female	Total - Male
0 - 15	58	24	23
16 - 19	1114	740	325
20 - 29	9385	6179	2800
30 - 39	10758	7274	3205
40 - 49	14148	9352	4542
50 - 59	20125	12717	7108
60 - 69	21402	11963	9134
70 - 79	16648	8512	7903
80 - 89	6258	3120	3059
90+	667	316	269
Total	100563	60197	38368

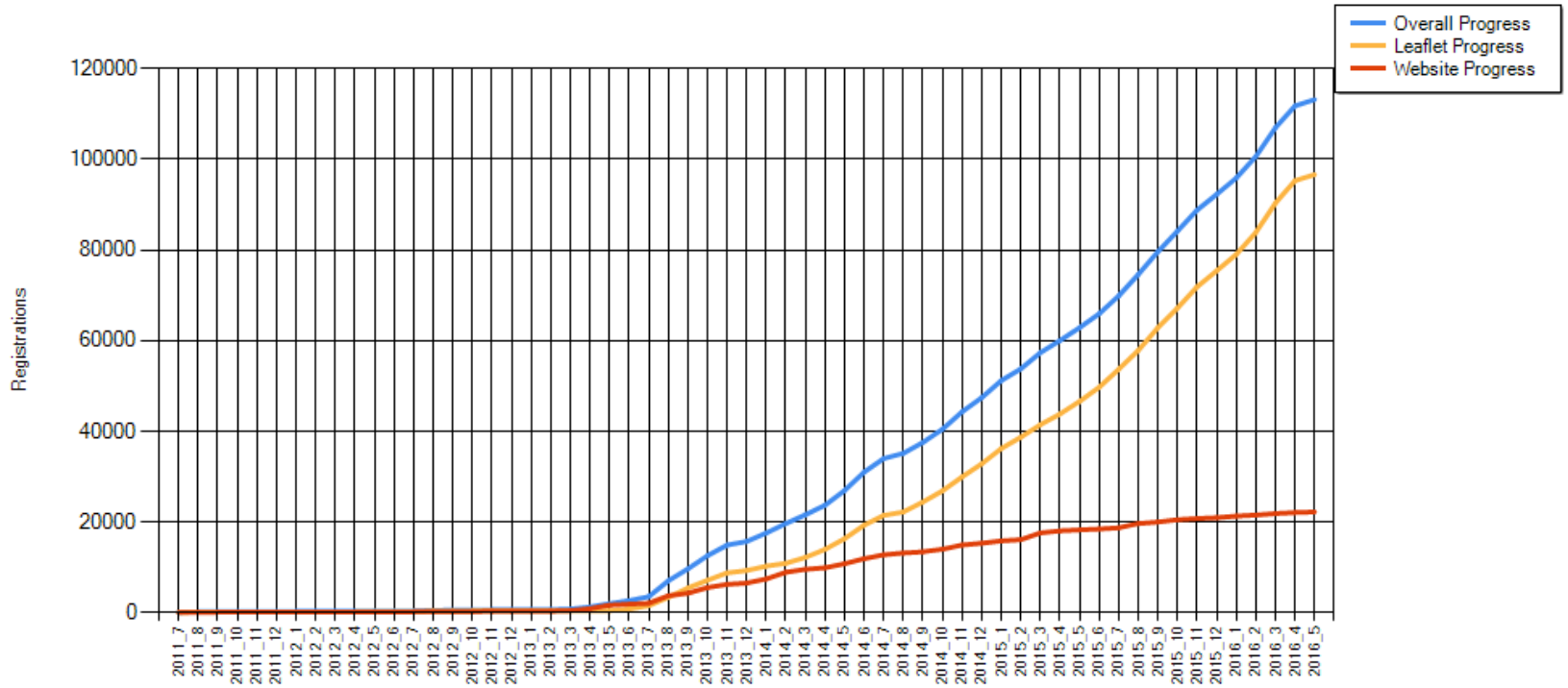
Recent projects

- We emailed a survey out to 50,000 participants within 2 hours
- Direct Diabetes Study: We found the last 8 participants in a week for a group who were 3 weeks from close of study were short of target.
- We have delivered 12 willing participants for a focus group looking at dental guidelines for patients on anticoagulants. These were contacted and delivered in 2 days.
- The most difficult, yet the most rewarding project was to persuade 150 healthy volunteers to undergo an endoscopy. We found them in three weeks.

Recruitment



Recruitment By Month (Accumulated)



We have 100,000 !!!!! In



SHARE Team

Maggie McCann
Louise Dow
Kirsten Cumming
Fiona Dove
Soha Elbatrawy
Emma Johnstone
Joanne Robertson
Cameron Shearer
Caroline Glen
Colin Palmer
Brian McKinstry
Sam Phillip
Roma Armstrong
John Haughney
Shobna Vasishta.

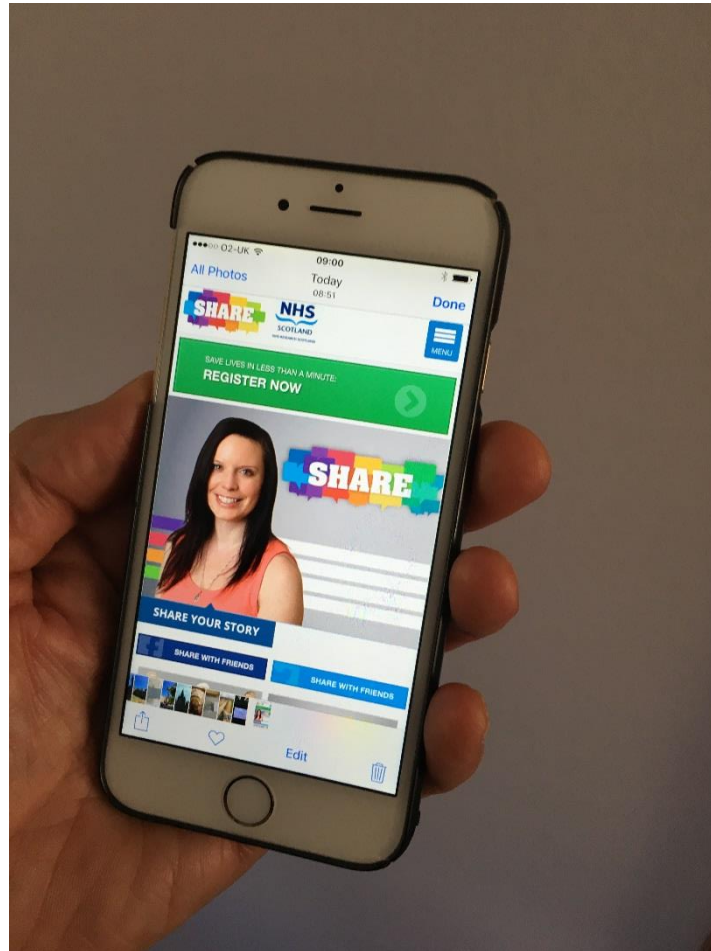
Lorraine Kelly SHARE registrant 100,000

What's New about SHARE?

- **Capturing Spare Blood!**
- Hundreds of potentially useful samples are discarded every day
- This blood can be used for medical research.
- Patients signing up to SHARE can allow their spare blood to be captured and stored
- This is an automatic process linked to CHI
- 25000 samples already stored



SHARE App





Recruiting for Research, Improving our Health

WWW.REGISTERFORSHARE.ORG