Increasing representation in clinical trials







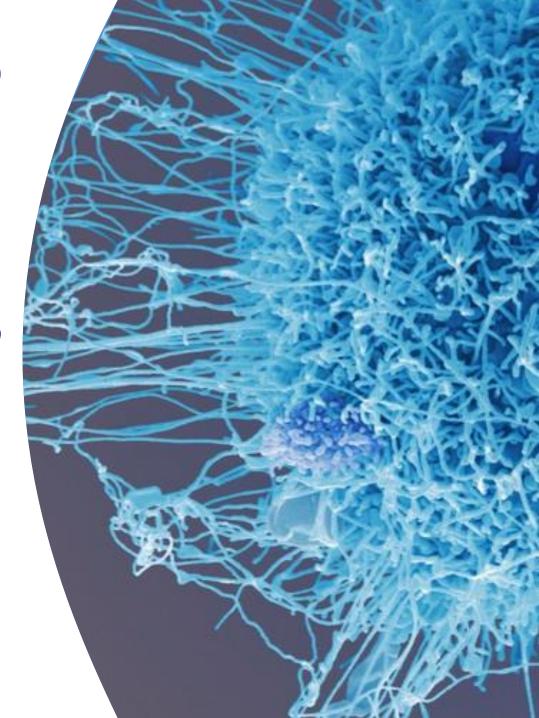


ECMC Network Meeting

Session: *Increasing representation in clinical trials*

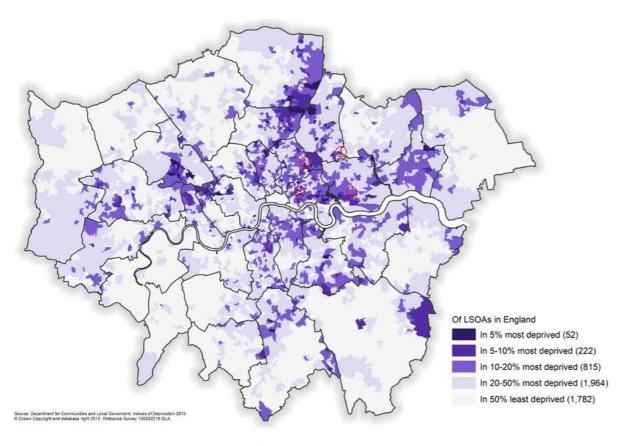
Dr Peter Hall 24 May 2023





Geography & Demographics





Source: GLA Intelligence Unit mapping of Indices of Deprivation 2015, DCLG

Geography & Demographics

Newham:

Protected characteristics

- 40% Christian | 32% Muslim
- Greater number of women amongst BAME groups
- Language: 60% English | 20% South Asian
- 32% White | 47% Black | 13% Asian | 8% Mixed Other (incl. 72.9%) BAME

Geography

- 17.9% over-crowded households
- 27.2% households renting from Local Authority or Housing Association

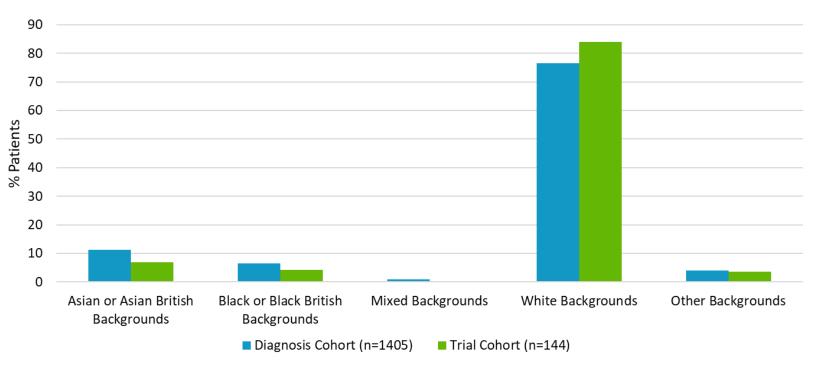
Source: Barts Health NHS Trust



Ethnic minority underrepresentation

Lung cancer at Barts

Patient Ethnicity in Diagnosis vs Trial Cohort (% total)



White backgrounds vs non-white backgrounds P=0.022



Projects

- PPIE group look beyond trial patients
- Patient website & Social Media
- Monthly online forum
- Patient videos:

This video is spoken in English with English subtitles.



This video is spoken in Polish with English subtitles.



This video is spoken in English with Bengali subtitles.



This video is spoken in Hindi with English subtitles.





Projects

International Clinical Trials Day event





Projects

• Outreach work – Lung cancer awareness with London Bangla Press Club:





Next steps

Pilot Project: Increasing representation of ethnic minority patients in breast cancer clinical trials







Sites:





3 parts:

Targeted content creation

Hospital-based role

Communitybased engagement

For further information:



Dedicated breast care nurse to work between breast clinics at Newham University Hospital and trials clinic at St Bartholomew's Hospital



Barts Cancer Institute Queen Mary University of London



ecme <u>www.bartscancer.london/centre-for-experimental-cancer-medicine/</u>

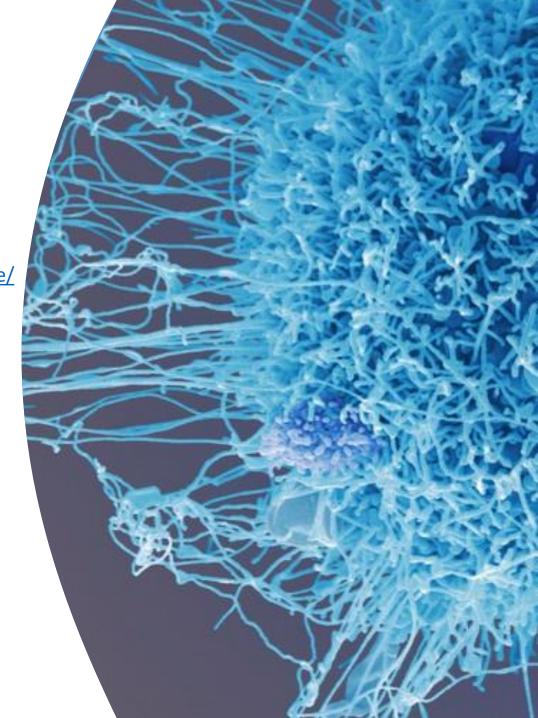


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Increasing representation in clinical trials session

ECMC annual meeting, May 24th, 2023

Dr Patricia Roxburgh, Clinical Senior Lecturer in Medical Oncology Glasgow ECMC









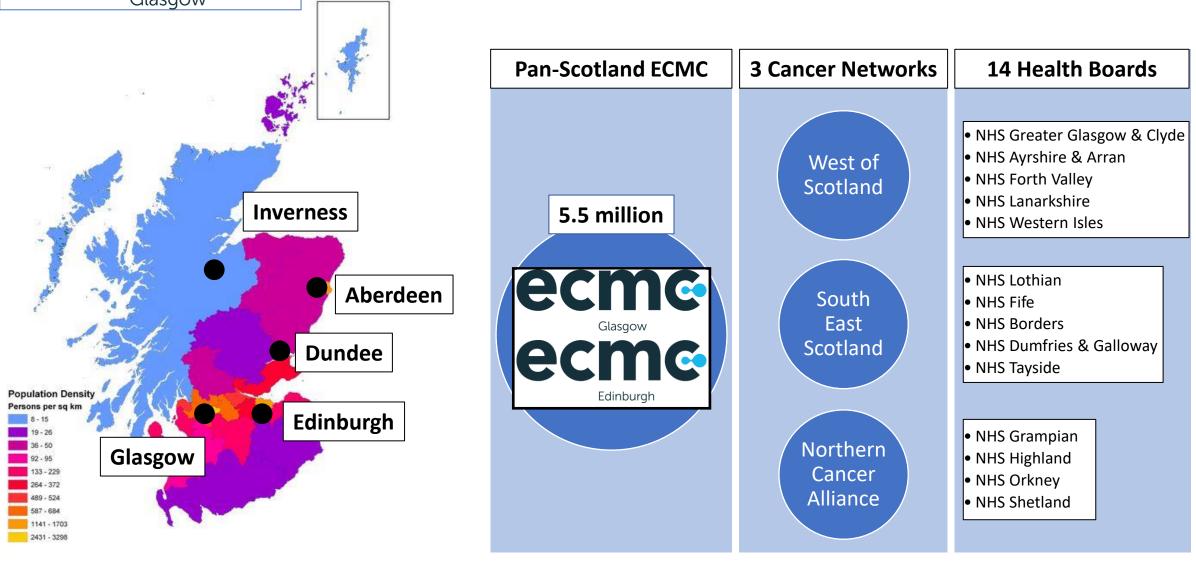






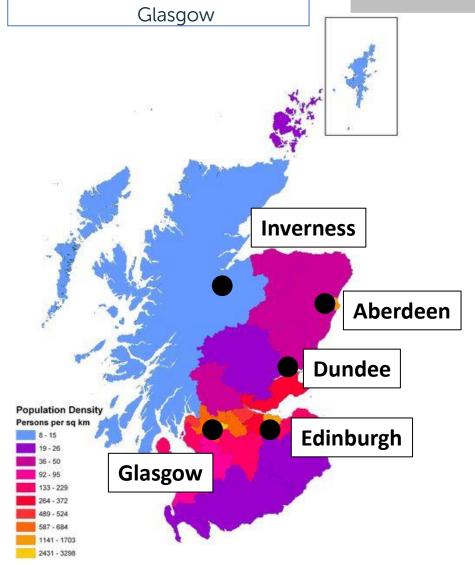


Geography & Demographics





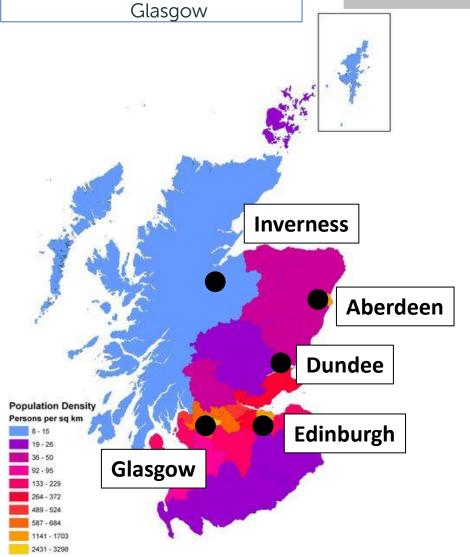
Representation challenges in Scotland

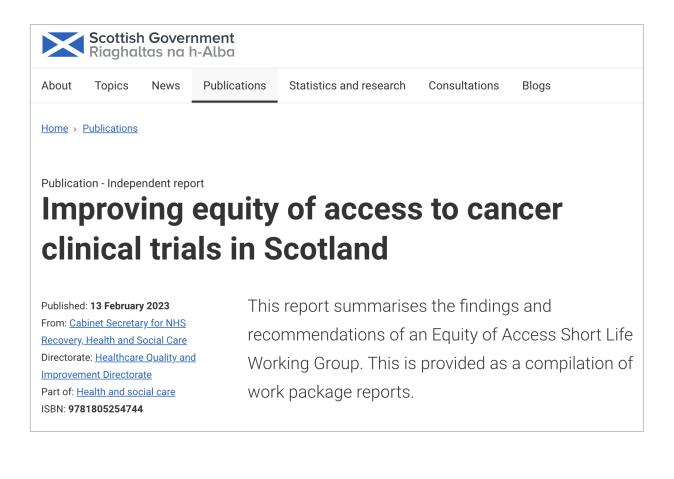


- 1. Wide socio-economic disparity
- 2. Participation in early-phase trials for remote communities



Representation challenges in Scotland



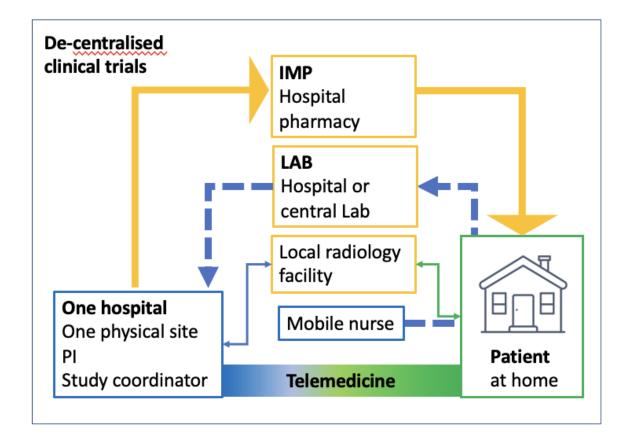




Two approaches so far

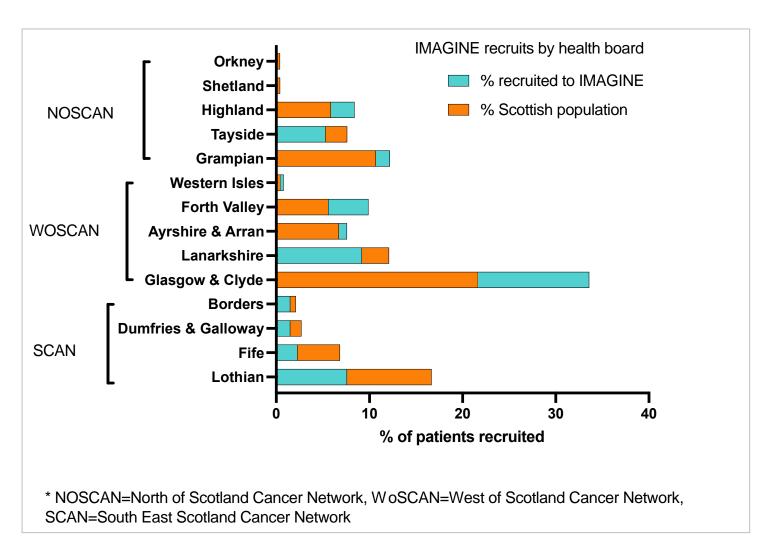


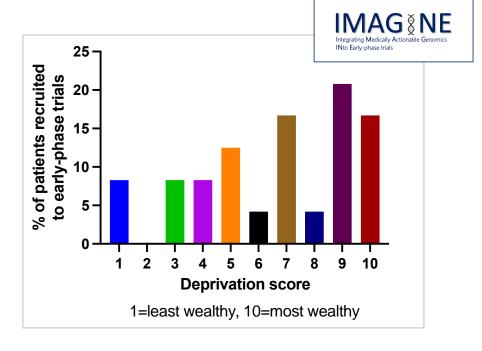
Widening access to genomics for early-phase clinical trial participants





IMAGINE recruits patients in all regions of Scotland and across all deprivation indices



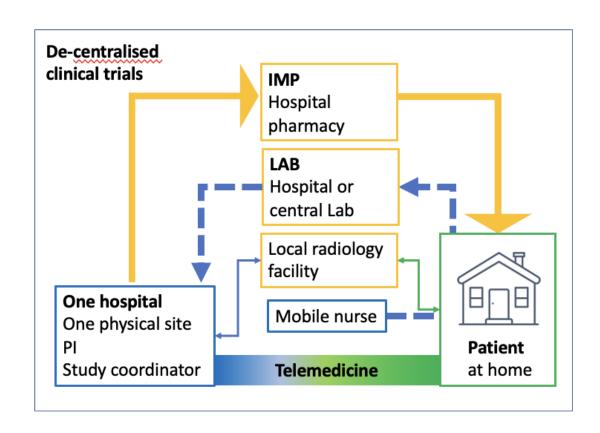


Areas for improvement:

- 1. Drive recruitment from Lanarkshire and Lothian
- 2. Consider how to increase participation of least wealthy patients
- 3. Increase participation of TYA patients



De-centralised clinical studies



Potential gains for all

Trial procedures performed near patient
More efficient to recruit rare populations
Removes burden/cost of travel
Improves patient participation/retention

Challenges for Regulators, Sponsors, Institutions, Investigators & Patients

Maintaining safety

Resources

Managing remote staff

Reliance on technology

Financial reimbursement at local sites



Learnings and next steps

To improve equity of access for less wealthy patients, remote communities and TYA patients, we plan to

- Invite representatives from remote regions to join our PPI panel
- Work with local volunteers and charities to support patient travel for clinical trials
- Develop more patient-centred approaches to clinical trial delivery, e.g. near patient "standard" assessments
- Develop a Scotland-wide collaborative group for cancer trials nurses to support cross-referral and cross-centre communication, reaching out to parts of Scotland without access to ECMC resource at their local Cancer Centre
- Ensure that reimbursement for patient travel costs is included in funding for non-commercial clinical trials
- Use telehealth where safe to do so and helpful for patient access







Fair and equitable access to phase I trials

Mary van Zyl Advanced Nurse Practitioner Drug Development Unit Royal Marsden Hospital and The Institute of Cancer Research 2. Investigating equality of access to the Drug Development Unit

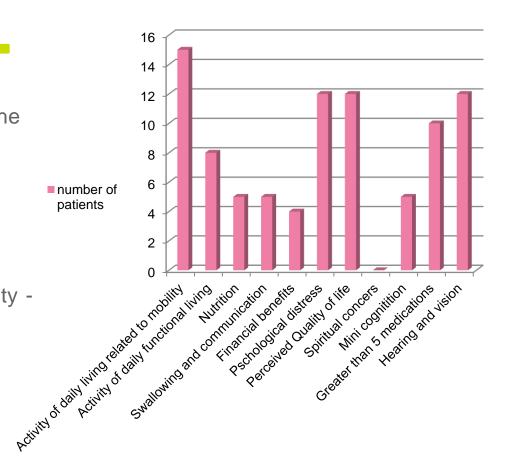
Assessment of Phase I Geriatric Oncology Project using SAOP3 tool

- Elderly population are under represented in Phase I trials and recruitment is challenging (DDU May 2023 58/180, 32% + 70)
- SAOP3 (Senior Adult Oncology Programme 3) tool validated short screening questionnaire
- Inclusion
 - Patients seen in DDU new patient clinic (solid tumours)
 - Age > 70
 - Assessed at visit as suitable for trial entry

Results

- 22 patients assessed over 33 clinics
- All patients approached completed the questionnaire in full
- Age range 70-78 (median 73.5)
- All patients triggered at least one domain for further assessment/intervention
- Average of 4 domains per patient
- Most common need related to mobility triggering the need for a physiotherapy/occupational therapy referral

Triggers for referral for each domain



Results

Free text section: "What matters to you?"

Core themes:

- 1. Family and friends
- 2. Positivity- not giving up, beating cancer getting treatment, hope and faith
- 3. Quality and quantity of life
- 4. Suicidal or negative thoughts
- 5. Occupation
- 6. Pets

Five patients (22.7%) failed minicognition test

- 18.2%, 4/22 deterioration resulting in trial ineligibility prior to consent signing
- 22.7%, 5/22 screen fail risk

- SAOP3 feasible
- High risk of deteriorating and screen fail
- Unmet need potential to optimise our older population

Assessing potential barriers to recruiting onto Phase I clinical trials

51 patients agreed to participate in service evaluation

Demographics

Social support

Employment statement

Housing status

Educational status

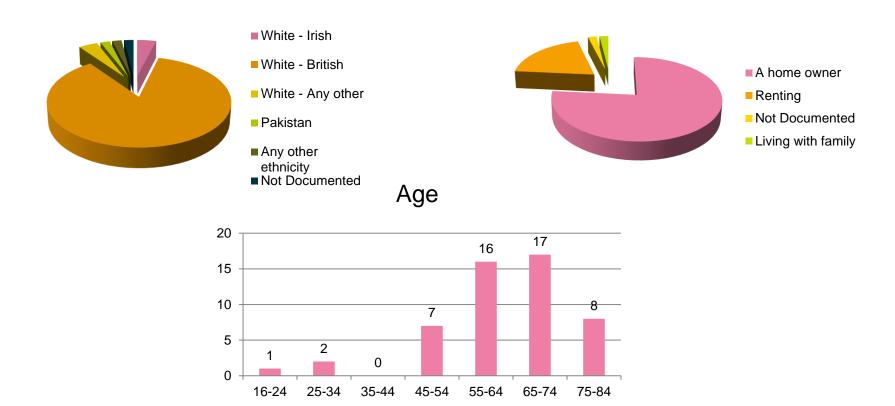
Triggers for referral to a phase I trial

15 Referring Oncologists sent online responses anonymously assessing barriers to referrals

What impacts the decision to refer

Barriers- age, distance, socioeconomic factors, language, time to discuss, patients eagerness to explore, disease burden.

Results – patient questionnaire



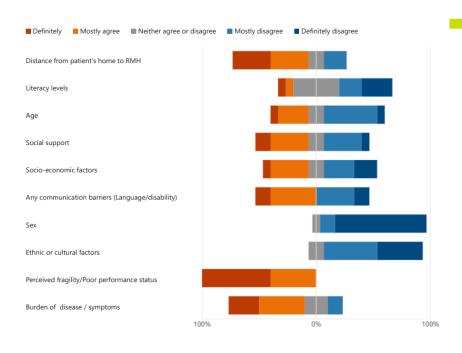
Results – patients questionnaire

51 patients

- 14 (28%) triggered referral discussion
- 19 (38%) oncologist triggered referral discussion
- 18 (36%) felt the discussion was joint
- Free text 5 patients mentioned travel time/distance being a restrictive factor.
 - "Travel & time spent at hospital"
- "Possibly the distance and the consideration of the side effects."

Results – referrers questionnaire

Could any of the following patient characteristics impact your decision to refer individuals for a phase I trial?



Other themes

Travel time and cost

40% of referrers were more likely to refer if patient was motivated to pursue trials.

40% of referrers felt time was limited to discuss phase I trials

Conclusions

- Population appears to be middle aged, white British population of reasonable financial security therefore barriers to diversity may be present
- Referrers and patients identified a number of ways to increase access to trials – common to both was cost/transport to site
- Some referrers felt that time pressures may impact decision to discuss Phase I

Future plans

- Links with RMH geri-onc group to explore prehabilitation for phase I elderly population
- We have established DDU specific PPI group to plan interventions to increase access to trials e.g video conference clinic, travel expenses for new patient visit, outreach to referrers

Thank you

To the patients participating in these projects

