

Sabrina Jarret Evidence Submission to APPG Call for Evidence

Based on your experience are there areas for improvement in donor recruitment strategies/relationships with community groups should address?

- Attrition (people signing up but not completing or backing out at donation) is often driven by fear, family pressure, or lack of culturally-trusted advice
- JP Morgan's was working on a project with Anthony Nolan - i was asked to participate and myself and a colleague were discussing cultural differences that affect attrition rates (donors continuing to donate) outcome was - building a trusting circle - confidants that potential donors could discuss with - to solve issue with attrition
- Orin & Bev (ACLT) offered this support in the past - & I mentioned it a year prior, but was restricted by AN through GDPR
 - GDPR is often used as a blocker rather than an enabler.
- Asia's Campaign on TikTok & Instagram - I made a couple of posts - culturally relevant, following a trend - made reference to her heritage - and the campaign saw x amount of registrations x% of those from her heritage [I need to find the statistics - will ask ACLT]
- The need for the registries to empower partners and patient families to scale
- Lack of partnership when patient campaigns came through meant that families has to find a way to reach out to all of us - to get wider spread messaging
 - Why: Families running urgent appeals currently must 'crowdsource' access to charities and registries; lack of contracted support delays scale.
- Working together with the registries for advisory, familiar with a couple times they have asked for support - but not in a contracted way or funded
- My experience at the WMDA conference, and 'be the match's' work to recruit diverse donors on TikTok, [I need to find the project and stats]

Is flexibility of recruitment with regards to age useful or a complication?

- Steve Marsh's commentary about 'even if we recruit all donors in the UK - gene mutation - not solving the issue
- Commercial interests vs. ethical - recruiting more British, European donors - because they are more likely to be called up for donation
 - Try! Because one may be better than none

- Optimal donor - age specific - typically known to better if they are younger, has no bearing on health. e.g. You could have a 20 year old that binge drinks vs. Femi - who was the only one match for a young girl - 36yrs old + and was able to recover very quickly. Then donating on three other occasions.
 - Why: Younger donors often provide better clinical outcomes, but age alone is an imperfect proxy for fitness or reliability. Messaging should encourage younger healthy people while not alienating older willing donors — and should stress that “one donor is better than none” when patients have limited options.
- Recent report - about black donors, not recovering well from donation - tends to defend the registries position to their motivations to recruit diverse donors.
 - Thus need to have cord blood readily available. Less of a match - but post stem cell transplant survivability rates are higher - but the speed to transplant is a familiar issues diverse patients face
 - <https://www.anthonynolan.org/blog/2024/11/28/new-anthony-nolan-research-ethnicity-affects-survival-after-donor-stem-cell?>
 - Why: Cord blood can be less HLA-stringent and is an important complementary resource for patients with rare HLA types; the aligned registry includes >28,000 searchable cord units but banked units from under-represented groups are disproportionately low.

How targeting should recruitment be and what does this mean in practice?

- Touch upon Asia's campaign again - which was mentioned in the question above.
- There are so many cultural/religious/generational nuances, - me as one person will not be able to answer for all. Working as part of a collective team creates the contribution to a campaign - ACLT are diverse, but our efforts to recruit from the African Caribbean community are far greater, because the majority of our team are from those backgrounds. Some with years of experience in recruitment, some with a touch of relevance to the youth, and engaging via different channels. [% of donors which are diverse - from our recruitment numbers]
- the term 'Black' as an umbrella - it is so vast - south Africa and west Africans do not respond the same - Caribbeans are all very different. Jamaica alone will tell you that.
 - This is just heritage. Not even touching on the surface of religion or generational trauma.

- Ellis's stem cell match campaign - mixed heritage with Antigua - yet - most F2F donor recruitment was targeted in Wales. My plea to the family was to keep opening doors with the black community in Bristol - and our work in west midlands and London - because of the diversity. Antigua has X amount of residents living in the UK - could we all have strategised better - to create a different outcome - or perhaps, we should have focused our efforts in recruiting cord (I guess - it costs more - and we do not have the infrastructure - so it wouldn't have mattered)

ACLT recruits people to be stem cell, blood, and organ donors at the same time, is this more difficult to get people to agree on?

- Typically, more work needs to go into recruiting diverse donors, because of the cultural, religious, and generational nuisances to overcome.
- For me - it was not hard.
- For the best part - most people remember what motivated them to donate - who they signed up for, where they were. It's not hard when there is more representation. Positively - When you click on a link and marketing is diverse. Or perhaps, questions were answered before you asked them because that would give you confidence you're understood.
 - Generational trauma does have an impact
- for donation - and attrition 'when there is a big decision to make - who do you trust to support you make your decision' - pastor, Iman, parents [wmda stats]?
 - There is no personalisation when called up to donation
 - E.g. Femi's one of the diverse donors - his family were very worried - his sisters did not want him to donate - and he could have easily backed out of his decision.
 - Why: Families like Femi's worry about safety and social pressure. Donors are more likely to proceed when their family/faith leaders are reassured and when the registry assigns a named contact who explains the process in culturally familiar terms.

Does competition work to improve recruitment drives or not?

- Healthy collaboration generally produces better outcomes; competition can drive PR wins, but patient-centred coordinated campaigns and pooled resources often deliver larger, sustained increases in registrants and reduced attrition.

- What's are the registries biggest motivator - to get to 1million stem cell - to ensure donors centres are fully booked. Is the culture of the company patient focused, or commercial outputs? More recruited - possible greater outcome? - or, 'it makes me look good'
 - Think about where you're best placed as an employee - team work often drives greater outputs - e.g. radio for John's that PR of DKMS organised - but the representation was an English woman - this was not significant to the target of recruitment.
 - Another significant experience of mine was when on the back of the donor leaflet - there was a QR code for financial donations. - do you want to recruit donors or raise funds?
 - Why: Competition for donors or PR can produce one-off sign-ups but undermines coordinated long-term recruitment. Joint campaigns (shared messaging, pooled geo-targeting, shared KPIs for diversity) yield larger, sustainable gains — e.g., radio or PR placements must include culturally representative spokespeople for the target audience.

How understanding different cultures can help recruitment and in reducing attrition rates when potential stem cell donors are called to donate

- State of the registry - tells you the answer [stats for 2024 recruitment] Yes - most recruited are British - and the growth in black donors, is marginal
- It does
 - Representation is needed to overcome the first barrier
 - Marketing that's appropriate and translates e.g. DKMS have done a great job with the 'auntie's campaign'
 - Use of third parties for advisory e.g. word on the curb

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