**Trustee Webinar September 2023**

**Summary Notes**

The Webinar was attended by **28 beneficiaries** and **five Trustees** (Mark S, David, Adrian, Caroline and Rosemary).

The theme for discussion was the Trust’s **Plans for Beneficiary Engagement**

A number of positive comments were made by beneficiaries:

* It’s a good idea to get a broader group of beneficiaries involved – for example wheelchair-users, four-limb affected, beneficiaries with sensory impairments - all having a voice and an opportunity to make Trustees aware of the challenges they face every day.
* By engaging with more beneficiaries there will be a greater opportunity for Trustees to gain a better understanding of issues/experiences that they may not have been aware of.
* The NAC effectively acted as a filter between the beneficiaries and Trustees – and some beneficiaries did not feel they represented them effectively. The new approach provides opportunities for Trustees to hear directly from beneficiaries which is a good thing.
* There will be a greater turnover of Panel members (as all will be appointed for a two-year term) This will allow more voices to be heard.
* Beneficiaries appreciate the opportunity to meet Trustees – whether at online events or in-person at Open Days/Local Events. Previously Trustees have seemed very remote.

There were a small number of concerns raised:

* Concern that the Beneficiary Insights Panel is being selected by Trustees rather than democratically elected by the beneficiaries.
* It will be crucial that Trustees meet beneficiaries face-to-face (for example at the Trust’s Local Events and the Thalidomide Society AGM) to genuinely understand their needs.
* Some beneficiaries were upset by the way NAC was disbanded so suddenly which seemed to come out of the blue.
* Sad to lose the NAC as they were so proactive in campaigning. There is a danger that the new structures are top-down, not bottom up like the NAC.

Some questions on Beneficiary Engagement were raised for clarification:

**Q: What will be expected of the Beneficiary Insights Panel?**

**A:** Trustees are looking forward to the next decade and really want to understand beneficiaries’ needs so that the Trust can change and evolve to meet them both now and in the future. The Panel will discuss emerging issues and topics that are important to beneficiaries that Trustees want to know more about. The role of the Panel is to share their personal issues, experiences and challenges so that Trustees hear first-hand what is important to different beneficiaries and can appreciate the full range of their lived experience.

**Q: The recent Diageo Chair’s Review was a success. Will we retain the same model of three beneficiaries/three Trustees/three staff members going forward?**

**A:** It is too early to say who will be involved in the discussions with Diageo in three years’ time but there were more than three beneficiaries involved last year. Trustees are really aware of the value of having beneficiaries sharing their lived experience with Directors of Diageo.

**Other Issues Raised**

A number of issues were raised by beneficiaries which did not directly relate to the Trust’s plans for Beneficiary Engagement but reflect the wide range of worries and concerns that beneficiaries have. These are summarised below, together with the action we have taken, or plan to take, in response:

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| **Issues Raised**  | **Our Response** |
| The challenges of adapting your home to future-proof it or needing to move to meet your future needs – and how to cover the costs of adaptations or moving to a new home. | We ran a session on ‘Financing Your Forever Home’ at the recent Future Money Matters event. The session was filmed and is available on our website.In our strategic plan we have identified the need to set up a Working Group of beneficiaries and staff to specifically look at the issue of housing options and major adaptations (this is scheduled to happen in 2025/26). |
| There is a crisis within the NHS and it is more and more difficult to access healthcare at a time when it is particularly needed by beneficiaries. | Our Medical Advisers are available to help and support beneficiaries to access NHS services.In addition, our Private Referrals and Private Treatment schemes allow beneficiaries to access private healthcare when essential services are not available on the NHS in an appropriate timeframe.For beneficiaries who need support with their mental health, we have established a Network of Mental Health Specialists. |
| Most beneficiaries are having more contact with the NHS as they get older, but many doctors and other NHS staff have no knowledge or understanding of thalidomide. | We have produced a range of resources for clinicians including the Resource Pack for GP practices, the emergency card and tailored resources for physios, anesthetists and OTs. These are all on the website or can be requested from the Trust,Having tried unsuccessfully for many years to engage a range of bodies including the GMC and RCGP, we have recently had some success in talking to ELAG (the Education Leads Advisory Group of the Medical Schools Council) about producing resources (such as videos) for undergraduate medical students on some of the issues that affect beneficiaries and also have wider relevance (e.g. ageing with a disability and working with patients who are resistant to taking medication). We hope this will help raise awareness and understanding amongst future doctors. There are also some local initiatives (for example a beneficiary working with Cardiff and Bangor Universities to raise awareness amongst medical students).We are also going to publish data on beneficiaries’ health gathered from HNAs in an academic journal and there is potential to speak to medical journalists to try to use this as a tool to raise awareness. |
| Additional care and support needs when in hospital (e.g. cutting up food/feeding, reaching water, charging hearing aids) | When we are aware that a beneficiary has a planned hospital admission, Trust staff will speak to ward staff to explain their additional needs. We have a designated member of the H&W team who has the lead role in supporting beneficiaries with planning for admission as well as supporting them while they are a patient and after discharge. We also provide simple aids such as laminated signs that can be displayed above a beneficiary’s hospital bed.  |
| The challenges of technology for people with disabilities – including inaccessible electronic payment systems in shops, carparks, road tolls – which can act as a barrier for many beneficiaries to do things they want to and limits their freedom. | In our Strategic Plan, we have identified the need to set up a Working Group of beneficiaries and staff to specifically look at the issues of SMART Technology and Assistive Technology.We can ensure that this group addresses the specific challenges of electronic payment systems.This is also a potential topic for a Focus Group or the Beneficiary Insights Panel. |
| The need for end-of-life support for beneficiaries. | In recent years, our Medical Advisers have provided support to a small number of beneficiaries at their end of life and we have asked them to identify whether these beneficiaries had different/additional needs to those they have supported in general practice.End of life care has also been suggested as a potential topic for discussion by the new Beneficiary Insights Panel to help us better understand the concerns and needs of beneficiaries in this context. |
| Challenges of accessing appropriate care when the informal support from family/friends is lost – especially with the pressures on care services | The first Beneficiary Insights Panel meeting (in March) will focus on the issue of care.The Trustees are going to discuss future care needs at their Awayday in June and the discussions from the Beneficiary Insights Panel will feed into this. |
| In the longer term, how will the complex needs of beneficiaries be met in a care home setting (it is difficult enough for people who have no disabilities)? | This is a complex issue and a potential future topic for the Beneficiary Insights Panel. |
| Will beneficiaries continue to receive lump sums every few years?How will the Trust begin winding down and use its money as beneficiaries die?  | Diageo have made it clear that beneficiaries should not assume that they will receive a lump sum at every Chairs’ Review.The ‘Asks’ we make of Diageo will be shaped by the views of beneficiaries and the evidence of need at the time of our discussions with Diageo – now scheduled every four years.Our aim is that by the time the last beneficiary dies, the funds currently held by the Trust will have reduced to zero – and this is one of the key challenges facing Trustees. Finance Committee (which includes a Trustee who is an Actuary) regularly reviews long term financial projections and we are currently on target.The Trust’s finances and how they work is a potential topic for a future Trustee Webinar. |
| How does the new Company, Thalidomide Voice, fit in? Some beneficiaries have concerns that they will jeopardise future discussions between the Trust and Diageo? | The Trustees know very little about Thalidomide Voice at this stage (no more than beneficiaries do) but they have no reason to think that they will jeopardise future discussions with Diageo. What was crucial at the last Diageo Chairs’ Review was the evidence from a large number of beneficiaries on their needs and what would help them most. All the new beneficiary Engagement mechanisms can only strengthen that evidence and that will be far more powerful than a small number of voices repeating well-known views. |

**Feedback from Attendees**

All beneficiary attendees were sent some feedback questions the day after the Webinar.

* 25 of the 28 beneficiary attendees responded.
* 23 said that they found the Webinar useful. 2 said they were unsure whether it was useful. None said that they did not find the Webinar useful.
* All 25 said they would be likely to attend a future Trustee Webinar.

In addition, beneficiaries had the opportunity to provide feedback in a free text format and the comments received will feed into planning for the next Trustee Webinar.