Infected Blood
Compensation Authority

IBCA response to community group sessions on registration and prioritisation

August, we held community group sessions to talk about registration and prioritisation.

Please see the published summary of those sessions for more details, and we have summarised the main themes in the table below.

The table below also sets out IBCA's response to the themes and suggestions we heard at these groups.

If you think we've missed any significant themes on registration and prioritisation in these discussions, you can use our feedback form to let us know.

We are now building the registration service and aim for it to be live as soon as possible, once we have taken this feedback into account. We will consider any other views raised through the feedback form in September before registration goes live. This will help us to decide if more development or other considerations mean we need to change our approach.

When we launch the registration service, we will keep testing it with people and developing it further as needed, based on your feedback.

We will also revisit how it works when we have built a fully digital claim service that is open to everyone. For example, we will then look again at suggestions from community groups about uploading evidence and checking eligibility to claim as part of registration, when the digital service is available.

Suggestions and views raised at community group sessions	IBCA response
Prioritising a claim based on age	
• different views regarding age being a set criteria • suggestion of prioritisations for those over 70 or 75 • links to bereaved elderly parents	With no majority view in community group sessions, we intend to follow the Inquiry's recommendation about age prioritisation (see page 184 of the Inquiry's additional report on compensation).
Prioritising claims for deceased infected (estates)	
• prioritise based on date of death or beneficiaries at end of life • prioritise parents who have lost children	With no majority view in community group sessions, we intend to follow the Inquiry's recommendations about prioritisation.
Linked claims (e.g. for families)	
• use of existing data to link family claims and gather family members' details within registration could reduce trauma • linking family groups could mean others of a higher priority are not able to claim first	Feedback raised concerns about the consequences of introducing this process, for example prioritising family members of a linked claim above others who may be facing circumstances such as nearing end of life. Linking family groups may be possible at a later date once claims are open to all. However, while we build the service we will prioritise based on the Inquiry's recommendations.
End of life criteria	
• there was concern that prioritising those at the end of life may inadvertently exclude those who are very poorly but do not meet a particular definition and IBCA should use discretion in those cases	There continues to be strong support for prioritising those who are sadly nearing the end of life. We have previously shared how this works on our website. We have also included below that we will develop an exceptions process for future groups of claims, to consider other exceptional circumstances.

Sharing where people are in the priority order	
• sharing an estimated timeline, when possible. • the majority felt that we should not share an exact order because dynamic prioritisation (where positions change based on people's circumstances) means it will not stay the same.	We will share timelines for starting new claims wherever possible, for example we aim to start some claims from all groups this year. We will not share exact places for an individual, based on community group feedback.
Evidence and documentation	
• gather information (for example medical documents) at registration stage • let people wishing to make a claim know what evidence they will require when they register so they can begin to gather it • include the IBSS reference field at registration, using this existing information by working with EIBSS and legal representatives • dedicated data gathering team to ensure quality assurance and reduce the burden on claim managers	We have considered asking for information at the point of registration, but this will introduce duplication of work while we build a claim service. This is because each claim manager will need to gather and consider evidence when a claim starts. Duplication of work will slow down the rate at which we can bring in and process claims. We do not intend to implement this while the claim service is being built, but will reconsider the suggestion when the claim service is fully digital and open to all. We will explore including the IBSS number (where relevant) at the point of registration. We have a dedicated data team, who work with those who hold the data (e.g. GPs, Haemophilia Centres, etc.)
Exceptional cases	
• ensure mechanisms for identifying and responding to exceptional cases, including consideration of homelessness as a factor for prioritisation	We will develop an exceptions process for future groups of claims.
Fraud	
• people are worried that self-reporting could allow fraud, so strong but fair safeguards are needed • increased risk for those	IBCA has fraud prevention measures in place, and will regularly update community members on fraud risks.

representing deceased infected (estates).	
IBCA operational capacity	
• more claim managers are needed to prevent delays and avoid claims being held back by complex prioritisation	More claim managers are being recruited every month, with the aim of around 500 in total. We'll keep this under review as the claim service develops.
Identity verification	
• gather evidence of someone's identity before they enter the service (registration) rather than when they start	While we initially build a claim service, requiring and checking evidence of someone's identity at the point of registration will duplicate work, as we also need to do this when they start their claim. Duplication of work will slow down the rate at which we can bring in and process claims. We do not intend to implement this while the claim service is being built, but will reconsider the suggestion when the claim service is fully digital and open to all.
Improving the existing claim process	
• create a dedicated IBCA team to work on claims from unregistered individuals	We are considering whether dedicated teams to deal with different types of work will be of benefit when we open the service more widely.
Incorrect data given that may impact prioritisation	
• differentiate between IBCA error, honest mistake, deliberate fraud • we should continue claims where someone has been prioritised incorrectly due to IBCA's processes • handling individual or official errors with flexibility and compassion	We will pause a claim where deliberate misinformation has been used for prioritisation, but will take a case-by-case decision where genuine mistakes are made by the person claiming.
Long term impact, fairness and justice.	
• acknowledgement of the time a	We will start claims for those who are

person has had an infection and life long implications. • concern this may prioritise those who are young and healthy over those who are older or sicker	living with infection and have never received compensation next, and will open the service for some people from the deceased infected and affected groups before the end of the year.
Prioritisation status	
• IBCA should share information about prioritisation status through clear and carefully managed communication to reassure people about how it's working and where they are in the claim process • include an opt-in (for more information) within the registration process • agreement that infected claims should be started first • acknowledged risks of tension if claims are fast tracked due to family links	We accept the Inquiry's recommendations on prioritisation. During registration, we will ask people for specific information that will help us with prioritisation, including whether they are nearing end of life. They can choose not to give us this information if they prefer.
Simplicity	
• a one-time registration process that captures all information and makes it clear what documentation will be needed in the future.	We will build a process that is as simple as possible, and continue to improve it where needed.
Speed	
• ensuring compensation is paid correctly at the fastest possible speed while reducing the burden on people making a claim.	We are committed to paying people as quickly as we can.
Working with the community	
• share materials in advance to enable better feedback • convert documents into surveys for wider consultations • publish notes for transparency and correction	We have published a summary of this session, and our response in this document, and will continue to do this for future sessions. If you have feedback on these notes, you can email us at ibcaenquiries@ibca.org.uk
Transparency	

• continued transparency about IBCA's decision-making process, information for those intending to claim and about any unintended mistakes. • psychological input into designing our processes and sharing materials needed to avoid trauma.	We will continue to share information on our decision-making, and the types of information we need to support each type of claim as we build the claim service further. We work with a clinical psychologist and IBCA user consultants to understand the impact of our work and take a trauma-informed approach, in addition to regularly working with members of the community.