

# Nominated Representatives v2.2

## Why have I been asked to be a Nominated Representative?

Research into conditions impairing memory and thinking is essential to increase understanding and improve treatment and care. Both people with memory impairment and those with no memory impairment who are interested in taking part as 'normal controls' are invited to participate in research. Most people will have the capacity to make the decision whether or not to participate in research. For some the capacity to decide may fluctuate and diminish greatly with time. If this happens their consent to participate can become invalid.

## What does it involve?

Nominated representatives are legal representatives appointed in advance by someone with capacity, in this context to confirm a decision regarding brain donation after death. A nominated representative can be a family member, unpaid carer or friend. They could also be the next of kin or person acting under Lasting Power of Attorney. It is often better to choose a representative who is younger than the participant as they are less likely to have their own health problems to deal with.

A nominated representative is appointed in writing, as part of the project consent form, by the person taking part in the research while they have capacity to do so. This person is then ideally placed to act as consultee under the Mental Capacity Act should the participant become unable to make their own decisions during the project. Briefly, the representative thinks about the wishes, feelings and previously expressed opinions of the person taking part in the research project and advises whether they would have wished to continue to participate or not. In no circumstances will the care of the participant be affected.

## Can you change a Nominated Representative?

Nominated representatives can be revoked or changed at any time by the participant. They just need to inform us.

# Newcastle Brain Tissue Resource

Information and  
guidance for  
Nominated  
Representatives