

## **About filming living donation transplants**

As a result of the media release on altruistic donations we have been contacted by a number of production companies. While we see the benefit of working with a production company following an altruistic kidney donation, we wanted to be up front about the difficulties of a project like this from the start. This is because we spent around 18 months working with a production company hoping to follow a paired transplant last year and they were unable to get the footage they required, so we understand the constraints and difficulties very well.

The difficulties include:

- to follow the process from start to finish takes time (for an altruistic donation there are a number of medical tests, a psychiatric assessment and the HTA independent assessment process)
- the transplant may not go ahead even if the person starts the process (for example, the person may not be medically suitable to donate, may develop an illness during the process or their personal circumstances may change which may lead them to change their mind)
- given the fact that altruistic donation is still very rare (only 23 people have donated in this way so far), it may be challenging to find someone who wants to donate and is happy to take part in the documentary
- the donors may drop out of the filming process at any time
- many altruistic donors choose not to meet (or be in any sort of contact with) those they donate to, something that you may be considering featuring in the documentary

## **Filming guidelines for following a living donation**

The HTA is responsible for approving all transplants involving living people, following an independent assessment process. The process ensures that the donor and recipient have been thoroughly assessed and understand what is involved in giving and receiving an organ, and that the risks have been properly explained. We are aware that media involvement could influence a donor's decision to proceed with a donation, particularly in relation to duress, coercion and reward. Therefore we would ask that anyone embarking on filming a living donation follow these principles.

- no payment should be made to donors.
- identities of donors and recipients should remain anonymous until after the transplant

Should media want to report on a potential transplant before it has taken place the following conditions should be followed:

- names of donors / recipients should be changed and it should be stated that they have been changed
- images of donors / recipients should be disguised, for example silhouettes should be used, or photographs should be taken from the back
- the location of donors / recipients should not be too specific, for example the region can be given but not the town or village they are from. For rarer transplants, such as altruistic donor transplants, even a region may reveal identity and this should be considered before proceeding with media
- locations of the transplant centres involved should not be made available to the donors or recipients
- the dates of the transplant and the centres involved should not be given in media coverage. Should a media release be issued with these details ahead of the transplant, the information should be under a strict embargo until the transplant has taken place

Documentary makers may be interested in following the process of altruistic, paired or pooled donation through from start to finish. Should they want to do this, they should do the following:

- anonymity of the parties involved must be retained ahead of the transplant going ahead
- being involved with filming should not influence whether the donor / recipient goes ahead with the transplant
- after the transplant goes ahead, the first contact with donors / recipients after the operation should be made by the transplant team rather than directly by the journalist. Donors / recipients should be given the option of whether they would like to continue with filming at this point
- donors / recipients should not feel pressured to take part, should know they can drop out of the filming process at any time, and should know they do not have to do follow up media after the documentary is screened unless they want to
- although donors / recipients can pull out of the filming process at any time, they should be aware that once they have taken part in filming and signed a release form, this footage may be used even if they drop out of the process (unless agreed otherwise before filming takes place)
- donors / recipients should be aware that if they agree to take part they may discover the identity of the other parties involved subsequent to broadcast