

## BACKGROUND

Health information has traditionally been stored on paper and generalised access has been limited by this. With use of new technologies to manage our health records, concerns are arising about who is viewing and using the information, while access by the citizens whose health information it is remains very difficult.

## SCENARIO

Barney has a family history of a common hereditary disease. Although Barney does not have the disease, he has consented, along with his brother, to being monitored by a specialist. They are part of a clinical trial of an experimental drug to prevent the disease developing.

Barney's information (along with information from other patients on the trial) are shared with a commercial third party.

Barney trips on a loose cable in work and has a fall. His employer insists he go to A+E. He doesn't tell the A+E doctor about his family history or that he is part of a clinical trial because he doesn't want to lose his place on the trial.

When Barney visits the specialist he doesn't tell him about the fall, but the specialist asks him about the A+E visit.

Barney is surprised that the specialist has seen the information from his A+E visit. He is also concerned about who can see sensitive health information that is in his record. He asks the specialist for a copy of all his information including any interpretations made by those who cared for him.

## DISCUSS

**Who should decide on the checks and balances for access to information?**

**Using the scenario discuss the consequences of access to (or restriction of access to) the health information mentioned in the story.**

## BACKGROUND

Information about our health is collected in many different ways by healthcare professionals. Information about sleep patterns, heart rate, breathing and movement etc. can also be collected by citizens using devices at home and on the move.

## SCENARIO

For the past 10 years, Sarah has had a long term condition that affects her movements and she experiences tremors. She sees a neurologist for this. Six months ago Sarah was told she has a heart condition which is now well controlled with medication.

Sarah has become very knowledgeable about managing her long term condition. She has an app that monitors her tremors when she uses her phone. She is finding out more about the new heart condition and she uses a lifestyle device to monitor her heart rate and her sleep.

While Sarah is well most of the time, she thinks the knowledge she has and the information she collects is useful both for her and when talking to her doctors, and could be useful for research.

Sarah visits her neurologist who is very interested in research. During the visit Sarah gives him a printout from her heart doctor which describes her new diagnosis. She tells the neurologist that there is an error on the printout about her medication. Sarah also gives him the information that was collected on her lifestyle device and on her phone for the last six months.

The neurologist is uncertain about including the information Sarah provided in her health record.

## DISCUSS

**Discuss the accuracy of the information described in the scenario from the points of view of Sarah and her doctor. Is accuracy of health information important?**

**What information described in the scenario is relevant for Sarah and her doctors to manage Sarah's conditions?**