## 

**Campaigning for the rights of older people**

***\*\**NEWS: *Immediate Release\*\****

*Fight to Stop Patient Data Grab Not Over*

**NHS Digital must keep word on Minister’s ‘tests’ to keep GP records secure**

**The National Pensioners’ Convention warns the battle over NHS Digital’s controversial GP ‘data grab’ is not over despite it being postponed.**

**While the NPC welcomes the government’s ‘three new tests’ to ensure the secure collection of 55 million patient files from GPs in England, the UK’s largest pensioners’ group remains concerned that they are already backtracking.**

The NPC and its coalition partners pressured NHS Digital into postponing the controversial move twice – on 1 July and then 1 September. But they warn they will continue to closely monitor the consultation process.

NPC General Secretary Jan Shortt said: “Millions of patients are still in the dark about this mass collection of their most sensitive medical files.

“Through pressure from our coalition campaigners to stop the GP data being taken and used without the consent of individual patients, NHS Digital and the government have taken a step back.

“While this is good news, we will be keeping a strict eye on what is done and said in the coming months, particularly on how they communicate with every household in England about their plans. Because so far, they have done virtually nothing to publicise them - not to mention that they have so far excluded huge numbers of people who cannot go on online either to find out about the collection, or to opt out from it.”

Government Minister for Primary Care and Health Promotion Jo Churchill announced on 19 July that NHS Digital’s data collection would be postponed until three new tests were met. These cover the ability for patients to opt-out of the data collection, assurances met on ‘approved researchers’ whom the files could be shared with, and crucially a ‘campaign of engagement and communication’ to increase public awareness and their choices.

**However, the NPC is concerned that the government is already backtracking after Innovation Minister Lord Bethel\* told Parliament’s health select committee just a day later – on 20 July - that he won’t commit to writing to every NHS patient to inform them about the changes to GP data.**

Jan said: “Just a day after the Minister, Jo Churchill, set out three tests – including increased communication with patients – Lord Bethel says they won’t be writing to individual patients. How can we trust either the government or NHS Digital to fulfil their promises on tests if they don’t notify all patients in person about what may happen to their health records?

“While the NPC appreciates the importance of health data being shared for vital research and planning, it is the process of sharing - and who with - that causes concern, along with genuine fears over lack of real transparency and our democratic right to choose how our information is shared and used.”

The NPC joined forces to stop the initial data grab on 1 July, with a coalition, led by the tech justice non-profit Foxglove that includes, Just Treatment, Doctors’ Association UK, all the Citizens, OpenDemocracy, and David Davis MP. Despite this latest postponement, the coalition is still prepared to take legal action if the rights of patients are not adequately protected.

The NPC written to all of its members to advise on their rights to opt out and how to notify their GP about their wishes on their personal files.

***ENDS***

\* LORD BETHEL EVIDENCE TO HEALTH SELECT COMMITTEE: <https://parliamentlive.tv/event/index/7fc6b404-0ea6-49ed-b5f4-e4ce923f7e28?in=10:47:56&out=10:49:20>

FOXGLOVE DIGITAL CAMPAIGN : <https://www.foxglove.org.uk/2021/07/22/the-government-has-scrapped-the-deadline-for-the-nhs-data-grab/>

NHS DIGITAL GP DATA COLLECTION: <https://digital.nhs.uk/news-and-events/latest-news/new-plans-to-increase-protection-and-strengthen-security-for-gp-data-collection-programme>

***NPC Background - NHS Digital GP Data Collection***

*The NPC recently became aware that GPs in England will be required to transfer patient data to NHS Digital without consultation. The only information available is a page on their website.*

***These are important points to understand:***

* *Patient choice is key to this whole process – because the launch of the data grab has been deliberately low key, very few people are aware of it, and that they can choose to opt out and keep their data private.*
* *The data being transferred is sensitive and could feasibly be accessed to other parties, some of whom may use it for financial gain.*
* *NHS Digital say patient records will be ‘pseudonymous’ (rather that anonymous) to protect people’s privacy – this means a code will be applied to each patient file, hiding the person’s identity. However, data experts say the code can be unlocked and the original details be made available to whoever holds the data.*
* *There is an opt out facility, but you need to go onto the NHS Digital website to access a form and send it to your GP.*
* *This digital opt-out excludes those (including many older people) who are not online, which breaches their human rights, and must be challenged.*
* *A coalition of concerned organisations (including the NPC) have issued a legal challenge to get the data grab halted for further extensive consultation and promotion of people’s rights concerning the data grab.*
* *Whilst we support the use of data for research purposes and developing new services for the future, it remains unacceptable that the process has not been open and transparent.*

**\*The National Pensioners Convention***was set up in 1979 to champion the rights and welfare of the UK’s older people. It now represents more than 1.5 million people in over 1,000 different organisations across the UK and holds an Annual Convention – a pensioners’ parliament - to debate issues affecting older people****.*** [***www.npcuk.org***](http://www.npcuk.org)

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