Cancer Research – Written Evidence (DAT0007)

Cancer Research UK's written submission to the House of Lords Inquiry into data adequacy and its implications for the UK-EU relationship (May 2024)

Summary

Cancer Research UK (CRUK) welcomes the opportunity to respond to the House of Lords European Affairs Committee inquiry into data adequacy and its implications for the UK-EU relationship.

Cancer Research UK is the world's leading cancer charity dedicated to saving and improving lives through research. We fund research into the prevention, detection and treatment of more than 200 types of cancer through the work of over 4,000 scientists, doctors and nurses. In the last 50 years, we've helped double cancer survival in the UK and our research has played a role in around half of the world's essential cancer drugs. Our vision is a world where everybody lives longer, better lives, free from the fear of cancer.

Sharing personal health data, with safeguards, is a vital pillar of health research cooperation. International collaboration is critical to the UK's research efforts to improve cancer outcomes and cross-border flows of personal data underpin these vital research studies. For UK-EU collaborations, this is facilitated by the EU's and UK's data adequacy agreements which enable the free flow of data between environments which maintain the relevant standards. The adequacy of the UK's data protection regime is crucial for CRUK-sponsored clinical trials involving patients and their families, researchers and institutions based in the EU. Cross-border collaboration is also essential to research rarer cancers, as trial participants from one country alone can't generate enough data to draw conclusions.

To maintain adequacy of the UK's data protection regime, UK data laws need to remain equivalent to those in the EU. If UK law were to significantly diverge from its EU counterparts, then there would be a risk of the EU not renewing or withdrawing its adequacy decision in June 2025. Alternative data transfer mechanisms (for example, Standard Contractual Clauses) would increase the cost of research through added complexity and legal fees. This could both deter EU-based research studies from involving UK-based researchers and patients and deter UK-led research studies from involving EU-based researchers and patients, reducing our ability to conduct life-saving cancer research.

Cancer Research UK recommends that:

i) **The UK Government and EU grant data protection regime adequacy to each other in their separate decisions due for review in 2025.**
ii) **Future changes to UK data policies, including the new Data Protection and Digital Rights Bill, must not put the EU's adequacy decision for the UK at risk.**
iii) **If the EU does not renew/withdraws its favourable UK adequacy decision, then the UK Government must share details of the precise replacement contracts as soon as possible.**

Cancer Research UK is a registered charity England and Wales (1089464), Scotland (SC041666), the Isle of Man (1103) and Jersey (247).

1. What is your assessment of the existing adequacy arrangement underpinning data flows between the UK and the European Union?
    a) What is your assessment of the value of the EU's adequacy decisions to UK organisations?

The adequacy of the UK's data protection regime is a key enabler of health data-sharing across borders including for research that looks to prevent, diagnose, and treat cancer. Science is global and international collaboration is crucial for progress. 61% of Cancer Research UK research published in the last five years involved international collaboration, with almost 80% of cancer researchers currently involved in multinational collaborations[1,2]. Almost all (90%) of paediatric trials carried out in clinical trial units we fund are international. As a research funder and advocate for cancer patients, Cancer Research UK has a strong interest in ensuring data can be shared effectively and safely across borders to ultimately improve cancer outcomes.

The EU's adoption of an adequacy decision on the UK's data protection regime on 28 June 2021 underpins vital cancer research collaborations between the UK and EU. Pan-European clinical trials, including cancer trials, need to routinely send patient data and test results across international borders. Lab researchers need to send samples. It is established practice that researchers across many disciplines share data across borders with appropriate safeguards. A CRUK researchers survey (2023) found that 89% of researchers think it's important that the UK and EU continue to allow scientists to share personal health data across borders with appropriate safeguards[2].

People affected by cancer don't just want scientists to collaborate; they tell us they expect them to collaborate – in whatever safe and appropriate way is necessary to beat cancer. Two CRUK patient involvement surveys

found strong support for data-sharing. One respondent said *"I am personally 100% all for sharing health data if it can help other people in the future and improve care/survival rates. If we would be able to do this information internationally too, then even better… We all want improved outcomes."*[3] And 99% of people affected by cancer agreed that our researchers must be able to start and continue new projects easily with partners around the world, including those based in EU countries; *"Collaboration and cooperation are key to high quality research. We need to support the very best research wherever it is if we are to improve outcomes for cancer patients and their families."* Response to our online survey from people affected by cancer 2023[4].

Cross-border collaboration is particularly important for rare and childhood cancers as researchers need to recruit people from multiple countries to make discoveries that improve patient outcomes. We know from our clinical research community that by bringing patient data together from countries across Europe, the rare then becomes not so rare.

Cancer Research UK has joined PRIME-ROSE, a Europe-wide effort to boost patient access to precision cancer medicine (PCM). The PRIME-ROSE consortium – funded by Horizon Europe – will come together over the course of five years and work with regulators, policymakers, healthcare providers and patient advocacy groups to implement evidence-based PCM in routine clinical practice. *"DETERMINE is an important new trial in the PCM space in the UK and provides crucial opportunity to explore the use of existing medicines in new cancer indications. Our collaboration with European colleagues within the PRIME-ROSE consortium will help speed up assessment of the role of these treatments across Europe and, together with regulating agencies, provide potential to bring new life-prolonging treatment options to patients with rare cancers"* Dr Matthew Krebs, Chief Investigator for the DETERMINE trial. The EU's adequacy agreement on the UK's data protection regime underpins the way personal health data can be shared within the PRIME-ROSE consortium. Without them, the UK would be a less desirable partner due to the paperwork that would be needed, in addition to a substantial amount of administrative support under existing arrangements.

Another example of a CRUK-funded programme that relies on the EU's adequacy decision to underpin international collaboration is the CONCORD programme for the global surveillance of cancer survival trends. It involves collaboration with over 300 cancer registries in 70 countries. CONCORD survival estimates are used by 40 national and international agencies, including the OECD, European Union and World Health Organisation. Co-Principal Investigator, Professor Claudia Allemani states *"We receive pseudonymised individual cancer patients records from over*

300 cancer registries world-wide, half of which are in Europe. Individual records are crucial for accurate estimation of survival probabilities. We need to obtain these data to produce the cancer survival figures that are necessary for policy-makers."

The EU adequacy decision about the UK's data protection regime avoids the need for costly and complex alternative data transfer mechanisms, such as Standard Contractual Clauses, to share personal data. These alternatives would increase the cost of research through added complexity and legal fees which could deter EU-based research studies from involving UK-based researchers, reducing patient access to life-saving research. **Our research community is clear that adding extra legal barriers in addition to existing safeguards will impede progress and damage the UK's position in the global research and development landscape.** In a recent CRUK researchers survey, 79% of researchers agreed that it has been harder to begin new collaborations with scientists and others involved in research activities based in EU countries since the UK left the EU[2]. CRUK's research community has already faced additional barriers to collaboration since 1 January 2021 and it is vital that they should not face new ones.

CRUK strongly recommends that the UK and EU grant data protection regime adequacy to each other in their separate decisions due for review in 2025. This is vital for cross-border flows of personal data required for life-saving cancer research, particularly in rare and childhood cancers.

b) How are the General Data Protection Regulation and the Law Enforcement Directive working in practice? What extra costs do they impose on businesses?

GDPR protects the privacy and security of personal data which is essential when sharing personal health data for research and maintaining public trust. Even if there are significant changes to the UK Government's new Data Protection and Digital Information Bill, researchers and organisations will likely need to abide by two different data protection regimes to continue to conduct their research with EU countries. This potentially doubles the amount of learning and increases the risk of mistakes, leading to increased costs compared to the status quo. GDPR is costly but the alternative is likely to be more costly. Any divergence from GDPR will mean that research will be unduly affected.

Some of our researchers suggest that some movement in GDPR might be helpful for research as long as it doesn't put the EU's adequacy decision at risk: *"I know the EU is looking to…review GDPR and that is an area that we sit in quite an interesting position in the UK because we're completely*

signed up to the principles of GDPR, which is good because that means we are a trusted country and we can share data with Europe. Nevertheless, we all know that there are huge problems with GDPR particularly in the realms of clinical research. And so again, there's an opportunity for the UK to look at that legislation and see if we can interpret and implement GDPR in a way that supports clinical research, but without deviating so far that we stop being a trusted country for Europe… I think as long as you stay within the framework, I think there are opportunities for UK interpretation to be more beneficial to research." Professor Pamela Kearns, Director of the Institute of Cancer and Genomic Sciences, University of Birmingham. Researchers can face significant challenges accessing personal health data; however, it is essential that any changes are carried out with careful consideration of the wider context, including the impact on public trust and data adequacy.

3. What implications, if any, would a no or disrupted UK-EU data adequacy scenario have?
    a) Do you have any concerns about the direction of travel of the UK Government's data policies as set out in the Data Protection and Digital Information Bill, and about the potential for greater divergence from EU data standards?

CRUK has some concerns about the direction of travel of the UK Government's data policies and the risk to UK-EU data adequacy. This is supported by independent analysis by UK in a Changing Europe which identified the risk of the EU removing its data adequacy decision for the UK[5]. The reforms to UK GDPR reduce some personal data protections that could prompt the EU to drop, or not renew, its data adequacy decision for the UK. The EU is also considering whether to reform its own GDPR rules which could complicate this decision further.

In February 2023, the Royal Society held a workshop exploring the scientific research implications to the UK diverging from the EU's GDPR[6]. This workshop convened scientific researchers, data protection experts, industry representatives and privacy campaigners. There was consensus that guaranteeing and protecting data adequacy with the EU was a key priority.

To maintain UK-EU data adequacy, and the vital collaborative research it underpins, the UK's data laws need to remain equivalent to those in the EU. If UK data law were to significantly diverge from its EU counterparts, then there would be a risk of the UK and EU data adequacy agreements not being renewed in 2025. **This outcome would mean that UK-based researchers involved in UK-EU clinical trials would need alternative data transfer mechanisms, for example Standard Contractual Clauses, to share personal data with their EU-based**

partners. These alternatives would increase the cost of research through added complexity and legal fees which could deter EU research studies from involving UK-based researchers, reducing patient access to life-saving research.

CRUK analysis shows that the UK's exit from the EU has created many barriers to global collaboration; it is crucial that we remove as many barriers as possible and not create any new ones. One respondent to our survey of people affected by cancer emphasised the importance of scientists being able to work together: "I don't care about geographical boundaries in Europe (or most of the rest of the world). I just care about scientists being able to work together."[4]

To ensure the UK remains a world-leading environment for cancer research that benefits patient outcomes, any future changes to the UK's data protection regime must not put the EU's adequacy decision for the UK at risk.

b) How high is the risk of the European Commission withdrawing its UK data adequacy decisions? What impact would that have and how prepared are businesses or the public sector for such a scenario?

Any significant changes in the new Data Governance and Digital Information Bill will risk the EU's favourable adequacy decision on the UK's data protection regime. The risk of losing adequacy status increases the further the divergence is from EU GDPR.

Withdrawal of the EU's adequacy decision will be complex, costly and burdensome to health researchers. It would lead to lengthy approval processes and cause significant delays in data-sharing therefore negatively impacting cancer research and discovery. Clinical trials take many years to set up, reach conclusions, publish and change outcomes for people with cancer across the world. **We must avoid creating unnecessary risks to existing and future trials.**

At least one senior scientist has told us that they might be forced to relocate if they can no longer complete their research in the UK due to data-sharing issues. This would be detrimental to collaborative research and negatively impact the UK Government's ambition to establish competitive advantage in attracting international talent to the UK[6].

If the EU were to withdraw its adequacy agreement for the UK's data protection regime, the UK Government needs to share details of the precise replacement contracts as soon as possible. This is essential for the continuation of international trials involving EU member states, particularly for rare and childhood cancers.

References

1. Cancer Research UK internal analysis. International collaborations defined as one or more authors with an address outside of the UK; publications with dates between 2018 –2022 inclusive (last five complete years); Cancer Research UK publication set reported to ResearchFish. Conducted August 2023
2. Unpublished Cancer Research UK data. Survey of the Cancer Research UK workforce on International Research Collaboration. Conducted September 2023
3. Unpublished Cancer Research UK data. Survey of Children and Young People Panel on Global Research Collaboration. March 2024.
4. Unpublished Cancer Research UK data. Survey of people affected by cancer on International Research Collaboration. September 2023.
5. UK in a Changing Europe. UK-EU Relations Tracker Q4 2023. 2024. Available from: UK-EU Relations Tracker Q4 2023 - UK in a changing Europe (ukandeu.ac.uk) [accessed 18 April 2024].
6. Royal Society. Post-Brexit divergence from GDPR: Implications for data access and scientific research in the UK. 2023. Available from: Post-Brexit divergence from GDPR: Implications for data access and scientific research in the UK | Royal Society [accessed 18 April 2024].
7. Department for Science Innovation and Technology. UK Science and Technology Framework. 2023. Available from: UK Science and Technology Framework - GOV.UK (www.gov.uk) [accessed 18 April 2024].

Received 3 May 2024