Brexit means... what for patients?

BMA patient liaison group symposium
19 September 2017
Brexit means... what for patients?
I would like to welcome you all to this timely and important opportunity for us to ask what Brexit means for patients.

In medicine, one of the first things you learn is that there is no clear distinction between the political and the personal. Decisions made in London or Brussels reverberate in the lives and health of our patients. Whether it is cutting funding, reorganising the way that care is provided, or affecting a doctor’s ability to practise, actions have consequences.

The negotiations with the EU and the various upheavals in parliament have been presented as if their only impact is on the careers and egos of those directly involved. If only that were the case. Instead, the implications are practical, personal and profound. They affect our patients and the care we provide in ways that seem to get more difficult and far-reaching as Brexit approaches, rather than less so.

That is why it is so important that the BMA’s patient liaison group, for so long the valued critical friend of the association, ensuring that we always put the interests of our patients first, has been the guiding spirit of today’s meeting.

So now on to the issues, which are many and complex. I think it will be remembered as a great historical irony that the one issue on which people fixated during the referendum – the supposed £350 million a week coming the way of the NHS turned out to be a cynical manipulation – whereas the many real issues failed to surface.

Even 15 months after the referendum, there are politicians who would prefer to hide from these inconvenient truths behind meaningless rhetoric about hard or soft Brexits or gratuitous abuse levelled at other European countries.

But for us and our patients, we have no such luxury. These issues are real for us and real for our patients. What systems, for example, will we have in place for British patients to access services in the EU, and vice versa? What effect will there be on the regulation of medicines and clinical trials? And what will the impact be on cross-border co-operation between Northern Ireland and the Republic?

We are still far from comprehensive solutions in any of these vitally important areas, even though that Brexit is only a few months away.

What I can say, more positively, is that while the politicians have so far failed to deliver the answers, the BMA's public affairs teams in Brussels, working closely with our partners in European medical organisations, and across the UK, with many of our elected representatives, have ensured that no-one has been able to ignore the questions.

They have lobbied in key areas which have a major impact on patient care:
– The retention and recruitment of EU staff
– The mutual recognition of professional qualifications
– The protection of world-leading research and the collaborative work that underpins it
And finally, the defence of health and safety legislation that protects patients and doctors from the horrendous and unsafe working hours of the past.

While the political class has seemed to enter a state of denial from June 23rd last year, the energy and focus of so many of my BMA colleagues has been in complete contrast. They have and will continue to work tirelessly in the interests of protecting high quality patient care.

I look forward to a day that helps make the political, personal, and helps keep our patients central to everything we do and say.
Summary of the symposium

On 19 September 2017 the BMA patient liaison group held a symposium with 65 delegates to discuss how Brexit will affect patients and healthcare in the UK and EU. See appendix 1 for a list of organisations that attended the symposium and appendix 2 for the full programme.

The event was opened by Dr Chaand Nagpaul, BMA council chair, who stressed how the current negotiations have practical, personal and profound implications for patients, doctors and the wider medical profession. Dr Nagpaul emphasised the importance of the patient perspective to the negotiations and the value the BMA places on the work of the patient liaison group. Dr Nagpaul challenged attendees to consider the complexity of the UK’s withdrawal from the EU and the real impact the negotiations and their aftermath will have on patients.

Laying the ground for the discussion later in the day, Dr Nagpaul posed a series of questions that needed to be grappled with urgently in the Brexit negotiations such as what systems will we have in place for UK patients to access services in the EU and vice versa? What effect will there be on the regulation of medicines and clinical trials? And, what will the impact be on cross-border cooperation on the island of Ireland?

The importance of tackling such questions for the medical community and patients has meant that the BMA has been playing a very active role in the UK and across the whole of Europe working with its partners to make sure that the major issues that will impact patient care are at the top of policymakers’ minds, including the retention and recruitment of EU staff, the mutual recognition of professional qualifications, and the protection of world-leading research and the collaborative work that underpins it.

Setting the scene – opportunities and challenges

The first session, facilitated by Paul Laffin, BMA EU public affairs manager, set the scene of the event. Mr Laffin provided an overview of the BMA’s work in this area and where Brexit negotiations currently stand.

Jeremy Taylor, CEO of National Voices – an organisation representing 140 charities in England to help support patients to be in control of their health and care — identified the following key issues that may affect patients following the UK’s decision to leave the EU:

- Having sufficient suitable staffing in the NHS, social care and research;
- Access to healthcare in EU countries, including via the European Health Insurance Card (EHIC);¹
- Access to medicines and medical devices;
- The development of new medicines;
- The protection of public health; and,
- Cross-border collaboration.

Mr Taylor explained that National Voices is part of the Brexit Health Alliance. The aim of which is to ensure that patients and the health sector are supported as the UK leaves the EU.

¹ The UK European Health Insurance Card (EHIC) is valid for holidaymakers and temporary visitors who need to use the state health system while in another EU country.
He proceeded to outline the Alliance’s key asks:

1. Supporting maximum levels of research and innovation collaboration with the EU so UK patients can benefit from EU networks and clinical studies;
2. Ensuring alignment with the EU on the regulation of medicines and medical devices for the benefit of patient safety and access to treatments;
3. Preserving reciprocal healthcare arrangements for UK and EU patients;
4. Protecting UK and EU citizens from risks to health through strong UK and EU coordination on pandemics, other threats and health promotion;
5. Securing a strong funding commitment to the health sector and the public health sectors, ensuring that any shortfall is offset.

Mr Taylor also raised the point that the UK’s withdrawal from the EU gives the UK the opportunity to rethink how the UK recruits, trains and deploys health care staff; how it funds and organises services; and how it approaches health and wellbeing more broadly. He did add, however, that there are a number of risks for patients, such as losing current benefits, freedoms and rights; the additional uncertainty the negotiations were placing on patients and health sector more broadly; and the wider economic impacts of Brexit.

Professor Tamara Hervey, Professor of EU Law at the University of Sheffield, reminded the symposium of the central role the NHS had played in the referendum with the Leave campaign’s strong focus on the idea that leaving the EU would be financially beneficial for the NHS. These narratives around the NHS and its potential funding still endure and it is clear that the public deeply care about the effect of Brexit on the NHS.

Professor Hervey described three potential scenarios for the UK as it leaves the EU, however, she stressed that the current mixed messages from the UK government make it difficult to understand which of these scenarios is favoured and whether Brexit is achievable, particularly in the current timeframe of the Article 50 process:

i. ‘Soft Brexit’: This would include access for the UK to the EU single market for goods and services and vice versa as compliance with EU regulations would continue. In terms of people, this could include securing their current status and rights. In addition, this option would enable continued access to EU regulatory networks and systems and EU research funding.

ii. ‘Hard Brexit’: This scenario could mean sector by sector negotiation and would require transitional arrangements to be put in place before the UK leaves the EU. It could possibly include access to EU regulatory networks and systems.

iii. ‘Crash out’ Brexit (no agreement): This would provide the maximum uncertainty for the NHS and patients. There would be no agreement between the UK and the EU with EU-UK trade relationships based on World Trade Organisation law. People, such as doctors and nurses, would be covered by UK immigration law losing their rights and potentially ability to live and work in the UK. Products from the UK would have access to the EU single market only if EU compliant and vice versa, providing considerable barriers to the movement of medicines and the regulation of medical treatments and clinical trials.

Professor Hervey outlined the key implications for patients from Brexit from her perspective as:

- **Staffing**
  A significant proportion of the UK health and social care workforce comes from other EU countries with 140,000 EU nationals currently working in the NHS and social care system across the UK. One tenth of doctors gained their medical qualification in the EEA but outside the UK. On the island of Ireland health professionals work across the UK/Republic of Ireland border throughout their working lives. Since the Brexit referendum the number of EU nurses moving

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to the UK has been declining, with only 46 registering with the Nursing and Midwifery Council in April 2017. The inability of the government to guarantee their existing rights after Brexit, coupled with the falling value of their salaries in pounds, is making the UK a much less attractive place to work. In addition, to the current uncertainty of the status of those already in the UK and those coming to the UK before the UK’s withdrawal from the EU, there is also no clarity on what the future EU-UK relationship in terms of labour migration will look like.

– Medical research & teaching

Research and teaching hospitals are particularly reliant on EU nationals when recruiting talented clinical and research staff as the UK is currently regarded as a top place globally to build such a career. One in six university researchers are non-UK EU nationals. Their position is equally insecure to that of the NHS workforce. The UK government’s current position appears to be that overall immigration figures must be reduced. In addition, it appears that every economic sector currently reliant on EU nationals is asking for a ‘special deal’, which is hard to square with the government’s apparent intention to reduce immigration.

– Reciprocal healthcare

Under current reciprocal healthcare arrangements, the UK pays for the care of UK citizens elsewhere in the EU and vice versa. However, following Brexit there is a risk that 1.2 million UK nationals living in other EU countries will be liable to pay for their own healthcare. There are currently an estimated 190,000 UK pensioners living in EU countries who are receiving healthcare under the reciprocal ‘S1’ scheme. However, if these pensioners were all to return to the UK for their health needs (as is their right and considering the potential legal limbo they might find themselves in, they may well feel they have to) this would cost the NHS an estimated £979 million – around twice the amount that the UK government currently reimburses to other EU countries for their care. It would also require an estimated 900 extra beds to be made available (the size of two hospitals like St Mary’s Hospital in London) at a time when there is already a crisis in the supply of beds in UK hospitals.

– Health care products & clinical trials

A wide range of products are bought by UK-based health or social care providers from EU suppliers on a daily basis. These range from simple tongue depressors to positron emission tomography (PET) scanners. These products, and their components, are currently governed by EU law that secures their safety and protects consumers/patients. Pharmaceuticals currently enjoy marketing authorisations that permit their sale anywhere in the EU and supply chains typically involve several EU countries. In addition, clinical trials for pharmaceuticals are governed by EU law. All clinical trials are conducted in accordance with the Clinical Trials Directive until the new Clinical Trials Regulation 536/2014 becomes applicable. The UK government intends to secure legal continuity in the aftermath of Brexit through the European Union (Withdrawal) Bill. This will convert existing EU law into UK law. However, provisions such as Regulation 536/2014 on clinical trials – which ensures a harmonised procedure for the assessment of applications for clinical trials across the EU – are not covered by the terms of the Withdrawal Bill as it currently stands. The powers currently set out for Ministers in the Withdrawal Bill could also be a significant threat to patients depending on which Brexit scenario is adopted. If there is a ‘soft Brexit’, with a Norway-like relationship with the EU, regulations will remain harmonised with those of the EU, providing limited scope for any harmful changes for patients. If the UK chooses a ‘hard Brexit’ or crashes out of the EU then the implications are different with the possibility that standards may be lowered in order to continue to try to compete globally and/or align with the USA which has a less precautionary approach to medical product regulation than the

5 The S1 scheme allows individuals from one nation to receive ongoing health and social care in another, with the costs of that care met by the state that they would either ordinarily reside
UK. Such a deregulatory stance would most likely be coupled with aggressive reductions in corporate taxation, which would lead to questions where the future funding for the NHS would come from.

- Cross border collaborations
EU law and policy (and funding) currently support a great deal of cross-border collaboration and cooperation between the UK and the EU. The European Centre for Disease Prevention and Control is one example. The many health-related projects supported by the EU's current Horizon 2020 research and innovation programme, and prior Framework Programmes, is another. A particularly important one for patients is access to European Reference Networks for rare diseases (the UK participates in 22 of the existing 24 networks).

Accessing healthcare here and abroad: How Brexit will affect the treatment of visitors from the EU in the UK and vice versa?

Professor Hervey continued by outlining what to consider in the context of reciprocal healthcare under EU law. She highlighted that there are four main categories of people involved:

- UK citizens visiting elsewhere in the EU temporarily;
- Non-UK EU citizens visiting the UK temporarily;
- UK citizens resident elsewhere in the EU;
- Non-UK EU citizens resident in UK.

When referring to visitors, the key entitlements are covered by the European Health Insurance Card (EHIC) system. This allows for the portability of social security entitlements across the EU. In the EU, 50% of those who are entitled to an EHIC have one. There are big differences in coverage among Member States. In some Member States (for example, Italy, the Czech Republic and Switzerland) the EHIC is issued automatically, whilst others issue it on request. In addition, the period of validity varies significantly among Member States, ranging from six months in Poland to six years in Italy.

Under the EHIC scheme the vast majority of claims (90%) are settled between the EU countries concerned, and not with the insured person. Therefore the patient still receives healthcare free at the point of treatment. The widespread and well-established reimbursement scheme behind EHIC ensures there are no upfront payments and limits the financial burden on patients.

There are currently about 27 million people in the UK who have an EHIC card, which costs £150 million per year. The difficulty in the UK to recoup costs under the EHIC scheme are largely due to the NHS not being very good at knowing who is using the system. There are also around 53 million visits a year from the UK to EU and around 25 million incoming visits. Without access to this or a similar arrangement there will likely be people who, whether through inhibition of cost or their condition, will be unable to travel when previously they could.

A ‘soft Brexit’, where the UK agrees to comply with EU internal market law, could mean that existing rights remain. A ‘hard Brexit’, where there is a negotiated Withdrawal Agreement, future reciprocal healthcare agreements may be less extensive such as similar to the New Zealand or Canada model. Under a ‘crash out Brexit’, where there is no Withdrawal Agreement, UK nationals in the EU would not be guaranteed any access to healthcare under the host country’s system. There are some minimal rights under international law, such as access to treatment in the case of medical emergency.

8 J Pacolet & F De Wispelaere (June 2016), The European Health Insurance Card, European Commission, https://stps.dk/da/borgere/international-sygesikring//~/media/A8E78C9712848E0800D16C5241131A5.ashx
If the future UK-EU relationship does not include reciprocal healthcare, there will be some groups of people, such as those with disabilities, who effectively will not be able to travel to the EU.

**Future of cross-border healthcare: Impact on patient care in Northern Ireland and the Republic of Ireland**

**Dr Paul Darragh**, an Associate Specialist doctor working in Antrim, explained that Northern Ireland faces the same issues as the rest of the UK in terms of staffing, research funding, regulation and public health but Brexit could be felt even more profoundly there as it shares a land border with another EU country.

Evidence from Co-operation and Working Together (CAWT) to the Lords Select Committee on the European Union revealed that cross-border cooperation with regards to healthcare has increased in recent years. Figures show that between 2003 and 2015, over €40 million was invested in cross-border health and social care initiatives via CAWT, with additional project applications amounting to €53 million submitted in relation to acute hospital services, prevention and early intervention, tackling health inequalities and other services.

Health services in Northern Ireland and the Republic of Ireland working separately often do not have sufficient demand to provide cost effective, highly specialist medical services. The only viable way to deliver such specialist services to patients, such as the paediatric cardiology service, on the island of Ireland is to deliver these jointly; consequently, the last two decades have seen a significant expansion in the provision of all island healthcare.

Patients on both sides of the border benefit from the provision of out-of-hour GP services in Castleblayney, County Monaghan and Inishowen, County Donegal, as well as shared dermatology clinics at four sites along the border, and ENT Services at Monaghan Hospital and Northern Ireland’s Daisy Hill and Craigavon hospitals. Cross border collaboration has enabled ENT waiting lists in the Health Service Executive Dublin North East area to be significantly reduced by facilitating ENT consultants from Northern Ireland’s Southern Trust to practise in Monaghan Hospital.

Dr Darragh said that authorities on both sides of the border need to give assurances that existing arrangements and provisions would be maintained.

If after Brexit only Common Travel Area rules applied, then only UK and Irish nationals would be protected but not any medical staff from other EU countries. To sustain high quality, the mutual recognition of qualifications between Northern Ireland and the Republic of Ireland needs to continue.

The government must ensure that doctors in Northern Ireland and the Republic of Ireland maintain the ability to move freely between both jurisdictions to be able to safeguard the sustainability of vital health services in both countries.

In order to sustain the delivery of high quality all island services, it is vital that reciprocal arrangements, involving the transferability and recognition of qualifications for doctors, along with measures to ensure patient safety, are maintained once the UK leaves the EU.

The government should seek to put in place clear arrangements that could attract and retain highly skilled medical professionals in Northern Ireland.

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**CAWT is a health and social care partnership run jointly between the Health Service Executive in the Republic of Ireland and both the Health and Social Care Board and Public Health Agency in Northern Ireland. For more information please see:** [http://www.cawt.com](http://www.cawt.com)
Delegates’ perspectives

The effect of Brexit on the NHS and on patients more widely is something the public deeply care about. However, the implications of Brexit and how it will impact on the NHS are still unknown and will depend on a ‘final deal’ between the UK and the EU. This uncertainty and lack of clarity is making patients anxious. Some of the delegates commented that they were not aware of the variety of benefits that the EU offered before the referendum as this was not widely covered in the media.

In terms of possible Brexit scenarios, the option of ‘crashing out’ was seen as most harmful for patients. A key issue for patients is that the NHS is properly staffed and the workforce feels supported. In addition, the support the EU provides for patients (e.g. health insurance, collaborative networks, funding for research) was considered very important, however its future is now uncertain.

There is a lack of information available to the general public about Brexit’s potential impact on healthcare. Many of the issues covered in the press, for example, that Brexit could stop the supply of medical radioisotopes from Europe reaching cancer patients in the UK, are highly politicised and finding accurate information is difficult. The information issued by the government was considered very broad and it is difficult to translate this into how this would affect patients particularly those with complex long-term conditions who may wish or need to travel to Europe.

Healthcare professionals need to be informed of any regulatory changes so they are best able to look after patients. Patient groups need to be pro-active in flagging any issues that have not been ‘unpicked’. These issues will need close observation and lobbying from the BMA, National Voices and other parties to push for what is best for patients and the NHS to minimise any risks. At the same time it is important to focus on potential opportunities.
Regulation of medicines and clinical trials: How will leaving the EU affect access to treatments?

This session was facilitated by Dr Julian Sheather, BMA Specialist Ethics Advisor.

Professor Jean McHale, Professor of Health Care Law at the University of Birmingham, provided an overview of the current regulatory structures in relation to medicine and clinical trials and the role of the European Medicines Agency.

She made clear that there were huge uncertainties still existent in the future shape of the UK-EU regulatory relationship. If the UK is not seen as a primary market for pharmaceuticals after Brexit, drugs may not be introduced as quickly.

The new Clinical Trials Regulation will streamline and harmonise the application procedure via a single entry point, the EU portal (database). This will be brought into force in 2019 after the UK has left the EU. If these regulations are not adopted in the UK it may be deemed a ‘third country.’ Under the new Clinical Trials Regulation, if trials undertaken in a ‘third country’ are used as data to support a clinical trial application within the EU, then those trials must adhere to standards that are equivalent to those applicable in the EU. The government needs to consider how it aims to engage with the Clinical Trials Regulation as withdrawal happens.

Professor McHale closed by saying that without an agreement between the UK and the EU systems need to be put in place to address the approval of pharmaceuticals in the UK.

Medical and Healthcare Products Regulatory Agency (MHRA) Deputy Director Andrew Gregory said that the MHRA would like to continue to collaborate with the EU after Brexit although it is also working on contingency plans. These plans include exploring options such as a UK accelerated license. The MHRA was, however, not looking to establish a new regulatory agency. Even if the UK remains part of the EU’s medicines licensing procedures, Mr Gregory suggested that it may be possible that at the end of that process the UK gets a final say over the licensing of a medicine in a UK market.
Cross-border collaboration: what will be the impact of leaving the EU on existing collaborations for healthcare in the UK.

This session was facilitated by Lena Levy, Head of the BMA public health and healthcare team.

Professor Martin McKee, Professor of European Public Health at the London School of Hygiene and Tropical Medicine, provided an overview of possible future scenarios following Brexit and how these would affect cross-border collaboration. He was extremely critical of the UK’s approach to negotiations, which he characterised as reflecting a remarkable degree of ignorance about how the EU worked, a failure to agree a consistent or realistic position within government, gross misrepresentation of the facts by some senior politicians (including the now notorious £350 million for the NHS claim), and an inability by senior figures in the UK negotiating team to engage seriously in the process. In contrast, the EU’s position is clear. He expressed concern that the failings on the UK side mean that it risks stumbling into a catastrophic “no deal” situation.

Of the available options, he argued that, while remaining in the EU would be the best solution, the Norwegian model, while still complicated, would retain much of the status quo. It would likely to take several years to put in place all of the specific mechanisms involved in the Norwegian option, however it seems reasonable to assume that, with goodwill on both sides, some interim arrangements could be found. Unfortunately, the current UK government seems unlikely to accept this.

If the UK did not reach a deal with the EU, then a number of things could happen. First, profound damage to the economy, with the Office for Budget Responsibility forecasting a loss of £15 billion per year even with the best possible deal. Second, a severe shortage of workers, both in the NHS and other parts of the economy. In particular, he highlighted the severe threat to agriculture and food supplies. Third, government failure, noting evidence that the civil service was already struggling with work related to Brexit and the parliamentary timetable had effectively been emptied of other business. He also noted that there were
Many detailed issues that were not being addressed. These include the potential inability to exchange confidential information required for research collaborations and the future operation of reference networks. Health professionals could find that their qualifications, obtained in another country, are no longer recognised. Access to medical radioisotopes, which play a crucial role in diagnosing and treating cancer, may be restricted as these are mostly imported from the Netherlands under arrangements overseen by Euratom. A Freedom of Information request he had submitted to the Department for Exiting the EU confirmed that, despite issuing public reassurances that this was under control, it had no papers and had held no meetings on this issue.

Emlyn Samuel, Senior Policy Manager at Cancer Research UK, spoke about the potential impact of Brexit on research collaboration. He said that the UK government had made positive noises about the importance of the UK maintaining a leading role in science and innovation — it is 1 of the 12 negotiating priorities. The government also published a Brexit position paper on the importance of continued collaboration in science and innovation as the UK leaves the EU, which was welcome.

There are many areas where leaving the EU could impact on cancer research in the UK — including regulation, licensing, workforce and science funding. On regulation, 28% of Cancer Research UK funded trials involve at least one other EU partner. Partnering with other countries on trials has been particularly important for rare and paediatric cancers where patient numbers are smaller. Alignment with EU legislation related to clinical trials has been important. For example, in enabling enough patients to take part in trials so that there is sufficient evidence to provide new treatments to patients.

On licensing, Mr Samuel stated that the UK must continue to be able to work with the European Medicines Agency so that pharmaceutical companies are able to launch innovative treatments to market faster in the UK. This will ensure that patients have timely access. On workforce, researchers are at the heart of the breakthroughs that benefit cancer patients in the UK, in Europe and worldwide. 46% of Cancer Research UK PhD students and half of its research fellows are not from the UK. A priority is to ensure that the UK continues to attract and recruit global scientific talent. It is key therefore that the UK Government sends more positive and consistent messaging to the global research community, including those already based in the UK, and address clearly how this will be achieved alongside other policy aims to reduce overall migration. On science funding, the UK must strengthen its world-class science base by building on and developing new funding programmes and global collaborations. 50% of all cancer research involves international collaboration and EU funding provides around £1.5 billion per year, however, it is not simply the monetary value this funding provides but the fostering of cross-border collaboration which is so important.

Cancer Research UK, working with a number of medical research partners, commissioned a report to collect evidence on the value the UK brings to EU science and health. This found that UK-EU collaborations increase the impact of research publications — the citation rates (number of times research paper is mentioned in another research paper) reaches almost double the world average when there is UK-EU collaboration. In addition, the UK has contributed almost 20% of the total research work carried out within EU health research programmes.

The findings showed that UK made key contributions in five areas:

1. Advisory bodies, research networks, and policies that underpin research across the EU and its member states;
2. Participation in pan-EU clinical trials, providing notable leadership for rare disease and paediatric clinical trials;
3. Co-ordination and hosting of some of Europe’s unique large-scale infrastructures for medical research;
4. Development of new therapies and medical technologies that benefit EU patients, backed by a thriving pharmaceutical and biotechnology sector;
5. Training early career researchers from across the EU, to develop their skills and launch their research careers.

In addition, the UK Government should prioritise UK alignment with the new Clinical Trials Regulation, which the UK has played a key role in shaping for the benefit of UK research. In particular, it should ensure participation in the central review process for approving clinical trials, which will provide UK researchers with access to the new EU portal and database.

Professor Jill Clayton-Smith, Network Coordinator of the European Reference Network on congenital malformations and rare intellectual disability, explained that rare diseases are difficult to diagnose and treat. Prevalence of these diseases are low and patients with these conditions will be spread across many countries as will be the experts to treat them. Collaborative research is therefore important as it allows health professionals to connect and share experiences, share diagnostic opinions, share expertise in best patient care, set up shared patient registers, and establish collaborative research studies.

There are a range of EU mechanisms which support cross-border collaboration: 24 European Reference Networks for Rare Diseases, the European Health Forum, the European Health Management Association, the European Medicines Agency, and research funding streams. European Reference Networks were established in order to build and disseminate knowledge on how to best diagnose, care for and treat patients with rare diseases; share knowledge and build expertise through enhanced teaching and training opportunities; shorten the ‘diagnostic odyssey’ for rare disease patients; and, enhance collaborative research.

There are a number of EU resources for patients, such as patient networks and the ability to travel for treatment via the ‘S2’ scheme. The EU has several ways of facilitating communication, for example, through ERN IT portals. If the UK pulls out of EU collaboration networks then access to patient registers and sharing diagnostic information may be more difficult.

13 The S2 route entitles patients to NHS-funded treatment in another European Economic Area (EEA) country or Switzerland as long as certain qualifying criteria are met.
Delegates’ Perspectives

Many delegates commented that the day had been very informative. Brexit may have damaging consequences for individual health, public health, healthcare professionals, and the funding of the NHS if appropriate steps are not taken to protect the health system in the UK. There is a clear lack of communication and understanding about Brexit. This could present an opportunity for the BMA and other organisation to provide informed material.

It is vital to find a way to give patients a voice in Brexit negotiations. ‘Patient power’ needs to be harnessed. It was considered that concerns about implications on patient care and the health service need to be raised with policymakers by:

- Providing forums, such as today’s symposium, to consider and discuss the implications of Brexit on patient care;
- Creating virtual networks to cascade information;
- Driving conversations through various organisations, including Royal Colleges;
- Finding examples and case studies that show the impact Brexit is having on patients and healthcare professionals. It was noted that earlier this year the BMA conducted a survey showing that many EU doctors in the UK are considering to leave; 14
- Finding opportunities to raise awareness of key implications that will affect patient care;
- Planning for various Brexit contingency scenarios including ‘crashing out’;
- Engaging with other interested stakeholders such as academics, researchers and doctors;
- Using social media to reach and mobilise the 60 million patients in the UK;

Despite the potential anxieties around Brexit, delegates also said that it was important to remain positive and take advantage of the opportunities to learn, brought about by today’s symposium.

Appendix 1

The attendees at the symposium came from the following organisations:

1. Academy of Medical Sciences
2. Association of the British Pharmaceutical Industry
3. Alzheimer’s Research UK
4. British Heart Foundation
5. British Medical Association
6. Cancer Research UK
7. Department of Health
8. European Reference Network Rare Congenital Malformations and Intellectual Disability
9. National Voices
10. London School of Hygiene and Tropical Medicine
11. Medical and Healthcare Products Regulatory Agency
12. National Association of Patient Participation
13. Royal College of General Practitioners (Patient and Carers Partnership Group)
14. Royal College of Nursing
15. Royal College of Obstetricians and Gynaecologists (Women’s Network)
16. Royal College of Paediatrics and Child Health (&Us)
17. Royal College of Physicians
18. Royal College of Physicians (Patient and Carer Network)
19. Royal College of Physicians and Surgeons of Glasgow (Lay Advisory Board)
20. Royal College of Physicians Edinburgh (Lay Advisory Committee)
21. Royal College of Psychiatrists (Service Users’ Forum)
22. Royal College of Radiologists
23. The Patients Association
24. University of Birmingham
25. University of Sheffield
Appendix 2

‘Brexit means... what for patients?’

09.30 – 10.00
Registration

10.00 – 10.05
Welcome
Speaker: Dr Chaand Nagpaul, BMA Council Chair

10.05 – 10.50
Setting the scene – What does Brexit mean for patients?
Facilitator: Paul Laffin, EU Policy Manager, BMA Public Affairs

Speakers:
– Jeremy Taylor, CEO, National Voices
– Professor Tamara Hervey, Jean Monnet Professor of European Union Law, University of Sheffield

10.50 – 11.20
Accessing healthcare here and abroad: how will Brexit affect treatment of visitors from the EU in the UK and vice versa?
Speaker: Professor Tamara Hervey, University of Sheffield

11.20 – 11.50
Future of cross-border healthcare: Impact on patient care in Northern Ireland and the Republic of Ireland
Speaker: Dr Paul Darragh, Antrim associate specialist in internal medicine

11.50 – 12.30
Table discussions
– What has particularly struck you from the morning’s talks?
– What have you found most pressing?
– What were you not aware of?

12.15 feedback from each table

12.30 – 13.15
LUNCH

13.15 – 14.00
Regulation of medicines and clinical trials: how will leaving the EU affect access to treatments?
Facilitator: Dr Julian Sheather, Specialist Advisor, BMA Ethics and human rights team

Speakers:
– Professor Jean McHale, Professor of health Care Law at University of Birmingham
– Andrew Gregory, Deputy Director, Head of EU, International and Strategy, Medicines & Healthcare products Regulatory Agency
14.00 – 15.00  Cross-border collaboration: what will be the impact of leaving the EU on existing collaborations for healthcare in the UK?

45 mins speeches – 15 mins Q&A

Facilitator: Lena Levy, Head, BMA public health and healthcare team

Speakers:
– Emlyn Samuel, Senior Policy Manager, Cancer Research UK
– Professor Martin McKee, Professor of European Public Health, London School of Hygiene and Tropical Medicine
– Professor Jill Clayton-Smith, Network Coordinator, European Reference Network, congenital malformations and rare intellectual disability

15.00 – 15.30  REFRESHMENTS

15.30 – 16.15  Table discussions & wrap-up

– What has particularly struck you from the afternoon’s talks?
– What have you found most pressing?
– What were you not aware of?

– Taking the day as a whole, what are the challenges you see as most concerning for patients, and what are the opportunities?

15.50  Feedback from each table

16.15 – 16.30  Closing remarks