

Institution: University of Bris	tol	
Unit of Assessment: 18 - La	aw	
Title of case study: Universi	ty of Bristol research reforms at	portion law in Northern Ireland, and
reproductive loss policy and o		,
Period when the underpinn	ing research was undertaken:	
September 2015 - 2020		
Details of staff conducting	the underpinning research fro	om the submitting unit:
Name(s):	Role(s) (e.g. job title):	Period(s) employed by
		submitting HEI:
Dr Sheelagh McGuinness	Reader in Law	08/2015 – Present
Dr Jane Rooney	Lecturer in Law	08/2016 – August 2020
Period when the claimed im	pact occurred:	
September 2016 – 2020	-	
Is this case study continue	d from a case study submitted	d in 2014 ? N

1. Summary of the impact

Research at the University of Bristol has led to reform of the law, policy, and practice that shapes reproductive experience in two key areas.

First, it provided crucial arguments that underpinned the successful campaign to decriminalise abortion in Northern Ireland and the resultant 2019 legislation requiring provision for access to abortion in the province.

Second, the research helped transform the care provided to those who experience reproductive loss – approximately 250,000 miscarriages and 3,000 stillbirths in the UK annually – through changes to the implementation of national guidance on the remains of pregnancy, pre-term birth, clinical practice and stillbirth registration.

2. Underpinning research

McGuinness and Rooney, at the University of Bristol (UoB), have led research on the regulation of reproduction, human rights and constitutional law, and healthcare law and policy. McGuinness' work advocates the importance of holistic regulation that facilitates optimal care and emphasises the role of law as a determinant of health. Rooney's work analyses the constitutional relationship between devolved and central government, arguing for specific division of competences for enforcing human rights obligations, specifically access to abortion care.

Abortion law reform

Both McGuinness and Rooney have undertaken research on abortion law reform. McGuinness' research [3.2, 3.6]:

- highlights how regulations are often a barrier to accessing abortion and hinder clinically optimal care;
- emphasises that a focus on abortion as an issue of 'moral' concern obscures understanding
 it as a fundamental part of reproductive healthcare and a human rights entitlement;
- argues for the importance of abortion care being integrated in healthcare systems and supported by the medical establishment.

Rooney's research [3.1]:

- highlights that under the Northern Ireland Act 1998, which implemented devolution in Northern Ireland, Northern Irish legislation must comply with human rights;
- emphasises that the domestic legal framework does not prevent Westminster from legislating for the devolved nations to ensure compliance with international human rights obligations, and shows that it is constitutionally appropriate for Westminster to legislate on provision of abortion in Northern Ireland because it is not only a health and criminal justice issue (devolved), but also a human rights issue (not devolved);
- concludes that it was not exclusively within the competence of the Northern Irish devolved bodies to change abortion law, and that the most viable way of ensuring Northern Ireland's law on abortion complied with human rights was an Act of the UK Parliament.



Transforming miscarriage and stillbirth care

McGuinness made a major contribution of legal expertise to the innovative interdisciplinary ESRC-funded project, *Death Before Birth* (DBB) [i], which drew on law, linguistics, cultural studies and anthropology. The project investigated: (i) experiences of reproductive loss; (ii) care and support in this area, and (iii) legal frameworks shaping experiences of loss. McGuinness' legal and policy insights [3.3-3.5] showed that the legal framework is often complex and poorly understood, with consequent negative impacts on care. In order to address this, she argued for:

- improvements to knowledge and understanding of the legally permissible options for disposal of pregnancy remains [3.3, 3.4];
- better support for women who experience miscarriage, particularly women who miscarry at home and are often not prepared for what to do with the remains [3.4];
- consistency in all aspects of care for those who experience reproductive loss [3.3-3.5];
- mitigating tensions between the legal distinction of miscarriage (pre-24 weeks' gestation) and stillbirth (post-24 weeks' gestation) and personal experience: the gestational stage is not necessarily a marker of the personal significance of the loss [3.4, 3.5];
- improving stillbirth registration to overcome the tension between a practice which originates in the monitoring of 'vital statistics' but is perceived by parents as primarily providing formal recognition that their child existed [3.3-3.5].

3. References to the research

- 3.1 **Rooney**, **J**. (2019) 'Standing and the Northern Ireland Human Rights Commission' 82 *Modern Law Review* 525-548; DOI: 10.1111/1468-2230.12417.
- 3.2 **McGuinness, S**. (2016) 'A Guerrilla Strategy for a Pro-Life England' 7 *Law, Innovation, and Technology* 283-314; DOI: 10.1080/17579961.2015.1106108.
- 3.3 **McGuinness, S**. and Kuberska, K. (2017). Report to the Human Tissue Authority on disposal of pregnancy remains (less than 24 weeks gestational stage) ISBN: 9780956838988; https://testprojectwebsiteblog.files.wordpress.com/2017/09/death-before-birth-hta-report-2017.pdf
- 3.4 **Austin, L**. and **McGuinness, S**. (2019). 'Reproductive Loss and Disposal of Pregnancy Remains' 70(1) *Northern Ireland Legal Quarterly* 131-153. https://nilg.gub.ac.uk/index.php/nilg/article/view/236/185
- 3.5 Kuberska, K., Fuller, D., Littlemore, J., **McGuinness, S**., and Turner, S. 'Death Before Birth: Liminal Bodies & Legal Frameworks' in Dietz, C., Thomson, M., and Travis, M. (eds) *Jurisprudence of the Body* (Springer, 2020); https://link.springer.com/chapter/10.1007/978-3-030-42200-4 7
- 3.6 **McGuinness, S**. and Montgomery J. 'Legal Determinants of Health: Regulating Abortion Care' (2020) 13 *Public Health Ethics* 34-40. DOI: 10.1093/phe/phaa014

Funding

- i. **McGuinness, S.** (Co-I) Death Before Birth: Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination and stillbirth. ESRC ES/N008359/1. September 2016 August 2018. GBP537,225.
- ii. **Rooney, J.** (PI) *Devolution in the UK and International Law.* Society of Legal Scholars Small Projects and Events Fund. (awarded December 2019) GBP3000.
- iii. **McGuinness, S.** (Co-I) Abortion & Travel: The Experience of Women in Northern Ireland Travelling to England to Access Abortion Care. Socio-Legal Studies Association (2016). GBP2189.
- iv. **McGuinness, S**. (PI) *Death Before Birth: Improving the experience of registering a stillbirth*. University of Bristol ESRC Impact Accelerator Award. April 2019 Ongoing. GBP16.000.
- v. **McGuinness, S.** (Co-I) *Death Before Birth*. University of Birmingham Impact Accelerator Funding September 2018 August 2019 'GBP6000.

4. Details of the impact

McGuinness and Rooney's research brings together key insights on the regulation of reproduction, human rights, constitutional law, and healthcare law and policy. This has led to: (1) The decriminalisation of abortion and subsequent provision of abortion services in Northern Ireland (NI); (2) UK-wide changes in practice, policy and training to improve support and care



from clinical staff, crematoria and General Registrars for parents who experience miscarriage or stillbirth.

1. Reforming abortion law in Northern Ireland

Prior to October 2019, abortion was criminalised in Northern Ireland (NI) with very narrow exceptions. This did not stop women in NI obtaining abortions but made it both difficult and unsafe. During 2019, McGuinness and Rooney provided expert advice to MPs on abortion law in NI and its human rights implications which played a crucial role in the successful campaign to decriminalise abortion in NI. This included providing written evidence to the pre-legislative committee on the Domestic Abuse Bill in April 2019 (originally the target legislation for an amendment on abortion law reform) where they set out key arguments for reform [5.1]. Their evidence, drawing on [3.1], made the case that it was constitutionally legitimate for Westminster to legislate to direct the Secretary of State for NI to change the law on abortion in NI, insofar as it was incompatible with international human rights law, specifically, the Istanbul Convention which seeks to protect women against violence. Their evidence also drew on [3.2] and [3.6] to detail what appropriate regulation of abortion in NI should be. In October 2019, McGuinness provided written evidence on the cross-jurisdictional implications of abortion policy to the British-Irish Parliamentary Assembly [5.1]. She provided expert advice in October 2019 and March 2020 on law and good clinical practice to Karin Smyth, Shadow Minister for NI, during debates on the abortion regulations for NI consequent to the 2019 Act (below) [5.2].

Most crucially, McGuinness and Rooney provided extensive advice to Stella Creasy MP, who in July 2019 tabled a successful amendment that became Section 9 of the Northern Ireland (Executive Formation etc) Act 2019. The amendment decriminalised abortion in NI and required the Secretary of State for NI to make provision for abortion services in the province. Creasy called on McGuinness and Rooney's expert advice, even on the day of the parliamentary vote on the amendment, to provide legal arguments demonstrating that human rights were not a devolved issue and hence remained with Westminster. McGuinness and Rooney advised both on the amendment's wording and the content of briefings used to garner support for it [5.2]. Stella Creasy summarises how their contributions shaped decision-makers' understanding of abortion law and led to its reform: "their research was extensively used in developing the campaign to decriminalise abortion in Northern Ireland...[and] provided the basis for [the] successful amendment...section 9 of the...[2019 Act]". Additionally: "Dr McGuinness' research argued that appropriate healthcare is properly determined in this context by the perspective of the individual...This concept underpinned the campaign for decriminalisation of abortion in Northern Ireland. [Her] work [also] provided a comparative lens through which to develop abortion policy for Northern Ireland, and her research into the shortcomings of abortion law in [other countries] provided a basis for how we conceptualised a human rights-based reform for NI. Overall, Dr McGuinness' research has had a clear and significant impact on MPs considering abortion law reform [in NI], and within the wider community of those working for [such] reform." [5.2].

Creasy further confirms: "Dr Rooney's research contributed to law change by enabling us to convince actors within the parliamentary process, clerks, and MPs that abortion was not an exclusively devolved issue...insofar as it was human rights incompatible, and that the devolution settlement legally required devolved institutions to legislate and create policy that was compatible with human rights. Her research enabled us to argue that it was therefore legitimate for Westminster to legislate to direct the Secretary of State...to change the law on abortion in Northern Ireland...Her arguments were vital in securing the political impetus for reform." [5.2].

In addition, a Parliamentary Adviser to Creasy detailed how Rooney provided advice: "literally while Stella [Creasy] was about to make the speech which won the first amendment which I truly believe is the vote that paved the way for decriminalisation. You can see on Hansard [Robin Walker, HC Debate (June 4th 2020) vol. 676, col. 1018] that the arguments you gave us on devolution and human rights were what won it in the chamber, and those arguments have now been taken on by the government are used by ministers to defend the [abortion regulations]." [5.2].

The Act came into force in October 2019 and abortion in NI was immediately decriminalised. Hence the prosecution of a woman for procuring abortion pills was formally dropped on 22nd



October (reported in <u>Irish Legal</u>)⁻ and the Abortion (Northern Ireland) Regulations 2020 came into force on 31st March 2020 with services established shortly thereafter, meaning women and girls were able to access abortion. While this landmark legal reform has yet to be fully implemented, it has allowed 664 women to access medical abortions in the six months to October 2020 (reported in the <u>Belfast Telegraph</u>), as compared to eight reported abortions in the year 2018/19 (<u>NI Termination of Pregnancy Statistics</u>). It enabled healthcare professionals who have been prevented from providing appropriate care to do so and removed the threat of prosecution for healthcare providers helping women to access abortions.

2. Transforming UK policy and practice for reproductive loss

McGuinness's research has improved healthcare and support services provided to parents who experience miscarriage and stillbirth. In the UK, approximately 25% of pregnancies end in miscarriage (250,000/year) and stillbirth occurs in 1 in 224 births (3000/year).

Development and implementation of national guidance

The Human Tissue Authority (HTA) has statutory responsibility for regulating the removal, storage, use and disposal of human bodies across the UK through its Guidance and Inspection procedures. McGuinness, as part of the ESRC-funded Death Before Birth (DBB) project [i], examined whether the HTA Disposal of Pregnancy Remains Guidance "(i) was being implemented; (ii) was known about by women; (iii) was fit for purpose" [5.3]. Her findings [3.3; 3.4] informed the HTA's position that, while the current guidance is "fit for purpose", there is a lack of informed choice and variation in the standard of information provided to women. This led the HTA to update "the advice and guidance we provide to the sector...and inspections of HTA licensed establishments" [5.3]. As HTA's Head of Regulation commented: "The valuable work from the [DBB] project has played a key part in our efforts over the last six years" to produce *"quidance that is relevant and meaningful"* for "potentially vulnerable" individuals. The DBB findings have also been used in guidance which informs clinical practice across the UK and provides the basis for hospital and clinic protocols on the management of pregnancy remains. The Royal College of Obstetricians and Gynaecologists incorporated DBB's recommendation for a standardised approach to provision of information about options for disposal of pregnancy. remains" in 2018 guidelines, whereas previous guidance did not address this at all [5.3]; and the Royal College of Nursing cite DBB in their national clinical guidance on miscarriage care (2018) [5.3].

Since its launch in October 2017, The National Bereavement Care Pathway (NBCP) has improved the quality and consistency of bereavement care provided by healthcare practitioners to parents following reproductive loss across UK healthcare settings. From the earliest stages, McGuinness and DBB's findings [3.3; 3.4] provided evidence-based recommendations for the NBCP. The UK Lead for NBCP states: "The DBB Report was used in a number of important ways in formulating the NBCP. The Report provided clear evidence for what we needed to make explicit in development of the Pathway. ... Furthermore, we also used the DBB in the actual development and progression of the pathway. The recommendations ... brought our attention to the importance of sensitivity, clear communication with parents, consent and parental choice ... These are areas... now fully incorporated in the NBCP documentation and guidance, which provides specific instructions [on] these issues." [5.4].

These areas appear in the NBCP's nine Core Standards and, as of July 2020, 69 of England's 137 Hospital Trusts had signed up to the NBCP. In an independent evaluation of the NBCP pilot in 2019, 89% of parents said they were communicated with sensitively; 89% felt the decisions they made in the hospital were the right ones. 76% of healthcare professionals who were aware of the pathway agreed that bereavement care improved in their trust during the pilot [5.4]. McGuinness was also a member of the *Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK* working group established to address radical variation in recording and reporting signs of life in pre-term births at the limits of viability. Her arguments for the importance of legal frameworks facilitating high quality clinical care [3.4] and the legal implications of inconsistent practice [3.6] informed the group's subsequent 'Guidance on Establishing Signs of Life in Babies Born at or Before Limits of Viability' (November 2020),



endorsed by all four governments and relevant Royal Colleges setting standards for UK-wide care [5.5].

New training resources

To ensure that professionals have access to the training and support necessary to provide excellent care to parents who experience reproductive loss, McGuinness and other DBB researchers worked with professional organisations to develop professional development materials using insights from the DBB project [3.3, 3.4, 3.5]:

- a. Two **Royal College of Midwives** iLearn Modules on 'Disposal of Pregnancy Remains' and 'Supporting Parents through Registration of Stillbirth' [5.6]. Available to approximately 4,000 midwives/support workers; completion contributes to on-going professional revalidation. According to iLearn's Professional Lead: "as a result of these modules, midwives, support workers and students are better equipped to provide effective and compassionate care and support for parents who have experienced pregnancy loss." [5.6].
- b. The **Federation of Burial and Cremation Authorities' (FBCA)** 'Best Practice Guidance for Infant Cremation England and Wales' training for the FBCA training and examination certificate for crematorium technicians, available to members at 236 UK crematoria. This training is the first in the sector to explain "the importance of recovering the ashes from a parent's perspective and provides examples of the types of uncertainty that parents express". FBCA's Secretary & Executive Officer explains "It was only through [UoB's] research, guidance and input that we became aware of the central role of the ashes to many parents and the important role they play for many in a healthy grieving process" [5.7].
- c. **Sands** (the leading stillbirth and neonatal death charity in the UK) and the **General Registrars Office** materials to improve stillbirth registration practice, including training videos and online materials for midwives and registrars [5.8]. According to Sands' Training and Learning Resources Manager, DBB "findings have been integral to informing and guiding our work with a range of professional bodies". [5.8].

5. Sources to corroborate the impact

- 5.1 **UK Parliament** (2019) Written Evidence to submitted the Domestic Abuse Bill prelegislative committee (DAB0407); **British-Irish Parliamentary Assembly** (2019) Report from Committee D (Environment and Social) on the cross-jurisdictional implications of abortion policy in the BIPA jurisdictions
- 5.2 Stella Creasy MP (2020) Supporting statement; Office of Stella Creasy (2020) Email correspondence Parliamentary Advisor to Stella Creasy; Sheelagh McGuinness (2019 & 2020) Email correspondence to Karin Smyth MP
- 5.3 Human Tissue Authority 18 February 2021 Supporting Statement, Head of Regulation; Royal College of Obstetricians and Gynaecologists (2018) Surgical Management of Miscarriage and Removal of Persistent Placental or Foetal Remains (Consent Advice No. 10 – Joint with AEPU) See: p.6; Royal College of Nursing (2018) Managing the Disposal of Pregnancy Remains: RCN guidance for nursing and midwifery practice: p.14
- 5.4 National Bereavement Care Pathway (NBCP) (2019) Supporting statement UK Lead; NBCP (2020) NBCP Impact Report publication and an important milestone; NBCP (2020) Progress Report
- 5.5 MBRRACE-UK (2020) National clinical guidance for the assessment of signs of life at birth in babies born before 24+0 weeks gestation where resuscitation is not planned (McGuinness membership listed on p8)
- 5.6 **Royal College of Midwives** iLearn Modules on 'Supporting Disposal Choices after Pregnancy Loss' and 'Supporting Parents through Registration of Stillbirth'; supporting statement (2020) RCM iLear Professional Lead
- 5.7 **The Federation of Burial and Cremation Authorities** (2020) Supporting statement Secretary & Executive Officer
- 5.8 **Sands** <u>Video</u> (available since March 2020) and <u>online material</u> to support professional practice on stillbirth registration, <u>and</u> <u>Supporting statement (2020) Training and Learning Resources Manager</u>