



Law Society  
of Scotland

# Advance choices, and medical decision-making in intensive care situations

Paper by the Law Society of Scotland

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## INTRODUCTION

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The Law Society of Scotland is the professional body for over 12,000 Scottish solicitors.

We are a regulator that sets and enforces standards for the solicitor profession which helps people in need and supports business in Scotland, the UK and overseas. We support solicitors and drive change to ensure Scotland has a strong, successful and diverse legal profession. We represent our members and wider society when speaking out on human rights and the rule of law. We also seek to influence changes to legislation and the operation of our justice system as part of our work towards a fairer and more just society.

Each year we undertake new proactive public policy projects to address areas of the law that have failed to meet the needs of our modern society or keep up with technological developments. This year, we have committed to considering reform of the law in the related areas of:

- (a) advance directives, and
- (b) medical decision-making in intensive care situations, including decisions about refusing or withdrawing life-sustaining treatment.

The conclusions and recommendations set out in this paper have been informed by a number of preparatory papers authored by members of our expert Working Group. These papers are published as Annexes to this paper, and can be accessed [here](#).

Note that we recommend that “advance choices” is more appropriate terminology than “advance directives”, therefore “advance choices” has been substituted in the title of this paper, and throughout it. Former terminology is used in papers reproduced in the Annexes which were written before the terminology in this paper was adopted.

### 1. Executive summary

The aim of the project is to consider and address current deficiencies in Scots law in relation to advance choices, and medical decision-making in intensive care situations; to advocate the need for Scots law adequately to address those deficiencies; and to formulate and offer proposals for legislative provisions for that purpose.

The first of those topics was originally described as advance directives, but we have adopted “*advance choices*” as being more accurate. Advance choices are instructions given, or wishes made, by capable adults concerning issues that may arise in the event of their incapacity. The issues may apply to all or any of health, welfare and other personal matters, to economic and financial matters, and to any act or decision intended to have legal effect, provided that it is not expressly excluded by law. “Instructions given” are intended to be binding, and we refer to them as “*advance instructions*”. Wishes made record the granter’s wishes, with the intention that they be taken into account and normally respected, without being binding.

We refer to them as “*advance statements*”. Particular considerations arise in relation to “*medical advance choices*” and “*mental health advance statements*”.

The second topic addressed is that of medical decision-making in intensive care situations, including decisions about refusing or withdrawing life-sustaining treatment. Where convenient, we use “*medical decision-making*” to refer to the whole of that topic. There are overlaps between the two topics, which is why they have been addressed in the same project. Medical advance choices have a potential role in advance care planning, and may be relevant in any situation where a need for medical decision-making arises. The only category of advance choices for which there is at present statutory provision in Scotland are mental health advance statements. We are aware that they are being addressed by the independent Scottish Mental Health Law Review (“SMHLR”), therefore they were not addressed in the Project, though we have coordinated and liaised with the SMHLR Executive Team throughout its work, to ensure mutual awareness, including in matters of common interest.

While the Covid-19 emergency has focused attention upon the shortcomings of existing Scots law in relation to both topics, both topics have become gradually more important over the years, as the human rights environment has developed and – in the medical sphere – with developments in medical knowledge and practice. Strong emphasis is now placed on the principles of autonomy and self-determination. The failure of Scots law to provide adequate mechanisms and clarity probably amounts to non-compliance with European and international human rights requirements.

Scots law in these matters is different from the law of England & Wales, but confusion and uncertainty is caused by the frequency with which propositions and advice based on English law are promulgated in Scotland without regard to the differences, leading to inappropriate practice and wrong assumptions. These include failure by medical practitioners in Scotland to realise that they do not have legal protection in some situations where their colleagues in England & Wales do.

This paper is based upon research and consideration of relevant human rights provisions, ethical considerations, existing Scots law, experience in England & Wales and elsewhere (including from the background to developments in England & Wales and elsewhere), and existing proposals for reform, clarification or creation of Scots law.

In relation to the principles of autonomy and self-determination, advance choices are placed at the top of any hierarchy, because they contain competent decisions, instructions and expressions of wishes by people themselves. They thus rank ahead of acts and decisions by persons appointed by them (such as attorneys acting under powers of attorney) and all measures taken or authorised by courts, administrative authorities or others (or by persons appointed by courts, administrative authorities or others).

However, particular issues arise because advance choices represent the decision and will of the person at the time when they are created, but become operable after a period of time (normally an unpredictable period of time) when the person no longer has the capability to review or vary the decisions already made. Inevitably, there may be situations in which the advance choice should be disapplied. This paper offers criteria for doing so.

Advance choices entail a tension between offering maximum availability on the one hand, and the need for certainty on the other. The solution which we offer is a range of possibilities. Certainty would be offered by “top-level” advance choices, for which maximum requirements and safeguards are suggested. Scope for disapplication would be minimised for top-level advance choices, and would be greater with greater degrees of informality. Provisions are offered to achieve and implement those variations.

This paper identifies, analyses and addresses all of the matters which – it is suggested – would require to be covered in legislation for advance choices.

As regards medical decision-making, having carefully considered all of the factors identified above, we offer a basic formulation (previously lacking) of the doctor-patient relationship, and resulting obligations, responsibilities and potential liabilities, in any situation where medical decision-making cannot proceed at all, or sufficiently quickly, in accordance with the competent and informed consent of the patient. The formulation is derived from existing principles in Scots law and some similar legal systems. Adequate clarity and certainty are however at present lacking in Scots law. It is urgently necessary to provide it, in the interests of doctors, patients and all others who might be concerned.

In the matter of withholding or withdrawing life-sustaining treatment, we have considered, commented upon and evaluated the 1995 proposals by Scottish Law Commission (which were never implemented), together with such case law as has developed, as a basis for formulating legislative provision that would provide the clarity, certainty and protections for medical practitioners acting properly, that is at present lacking in Scotland.

Our recommendations include suggestions as to how both topics may be taken forward to the drafting, introduction and implementation of legislation, including suggestions as to further research, consultation, and – following upon the introduction of legislation – a coordinated approach to all aspects of its successful implementation.

## 2. Project objective

The overarching aims of the Project are:

1. to consider and address current deficiencies in Scots law in relation to:

(a) advance choices<sup>1</sup>, and

(b) medical decision-making in intensive care situations, including decisions about refusing or withdrawing life-sustaining treatment;

2. to advocate the need for Scots law adequately to address those deficiencies; and

<sup>1</sup> “Advance directives” in the original remit.

3. to formulate and offer proposals for legislative provisions for that purpose.

### 3. Abbreviations and definitions used in this paper

“2000 Act”:	Adults with Incapacity (Scotland) Act 2000
“2003 Act”:	Mental Health (Care and Treatment) (Scotland) Act 2003
“2005 Act”:	Mental Capacity Act 2005 (England & Wales)
“Advance choice”:	Instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity, and which may apply to all or any of health, welfare and other personal matters, to economic and financial matters, and to any juridical act (see below) not expressly excluded by law from the potential scope of advance instructions given in an advance choice (see section 5.1 of this paper)
“Advance directive”:	The same as for “advance choice” (above)
“Advance instructions”:	Instructions given in an advance choice with the intention that they should have the same effect when they become operable as a competent juridical act (see below) at that time
“Advance statement”:	Wishes made in an advance choice
“Annex”:	Unless otherwise indicated, an Annex to this paper ( <u>Note</u> : For “Appendix” see the next entry below)
“Appendix”:	Unless otherwise indicated, an Appendix to Annex A to this paper
“CoE 2018 Report”:	Council of Europe Report “Enabling citizens to plan for incapacity: a review of follow-up action taken by member states of the Council of Europe to Recommendation CM/Rec.(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity”, prepared by Adrian D Ward, Consultant (Scotland, UK), on behalf of the European Committee on Legal Cooperation
“CRPD”:	The United Nations Convention on the Rights of Persons with Disabilities (13 December 2006)
“GMC”:	General Medical Council
“Hague 35”:	Convention on the International Protection of Adults (The Hague, 13 January 2000, 2600 UNTS)
“HCCH”:	Hague Conference on Private International Law
“ICU”:	Intensive care unit
“Juridical acts”:	Any act of the will or intention (other than a legislative or judicial act) which has, or is intended to have, a legal effect (see the full definition in paragraph 1.10 of SLC 1997, also quoted in full in paragraph 2.1 of Annex A

“Medical advance choice”:	An advance choice in relation to medical matters <sup>2</sup>
“Mental health advance statement”:	An advance statement limited to mental health matters, made in accordance with the provisions of sections 275 - 276C of the 2003 Act, or thereafter under any provisions replacing the same
“the Project”:	The project described in the Introduction to this paper
“recommendation”:	Unless otherwise indicated, refers to a recommendation in sections 7 to 9 of this paper
“Rec.(2009)11”:	Council of Europe Recommendation CM/Rec.(2009)11 of the Committee of Ministers to member states on principles concerning continuing powers of attorney and advance directives for incapacity (adopted 09 December 2009)
“SLC 1995”:	Scottish Law Commission Report No 151 on Incapable Adults, September 1995
“SLC draft Bill”:	The draft Incapable Adults (Scotland) Bill forming Appendix A to SLC 1995
“SLC 1997”:	Scottish Law Commission Report No 160 on “Interpretation in private law”, 28 October 1997
“SMHLR”:	Scottish Mental Health Law Review
“the topics” (in the Recommendations):	The topics identified as (a) and (b) described in the Introduction
“Top-level advance choice”:	An advance choice that complies with the requirements proposed in section 8.3 of this paper
“Working Group”:	The Working Group established to conduct the Project, as listed in the final section of this paper

#### 4. Context

The Covid-19 emergency has focused attention upon the shortcomings of existing Scots law in relation to advance choices, and relevant aspects of medical decision-making in an intensive care setting (including decisions about withholding or withdrawing life-preserving treatment, and about transferring patients to palliative care only). These are not however short-term concerns only. They have become gradually more important over the years, with developments in medical knowledge and practice. At the same time, the human rights environment has placed increasingly strong emphasis on the principles of autonomy and self-determination, and it could be argued that the failure of Scots law to provide adequate clarity for the

<sup>2</sup> This paper does not offer suggested draft statutory provisions. Terms such as “medical matters” would require review and definition for the purposes of legislation.

requirements and effects of advance choices (with the exception of the provisions for mental health advance statements under the Mental Health (Care and Treatment) (Scotland) Act 2003, (the “2003 Act”) probably amounts to non-compliance with European and international human rights requirements.

The topics of medical advance choices, and of refusal or withdrawal of life-sustaining treatment, were addressed in Scottish Law Commission Report No 151 on Incapable Adults (September 1995) (“SLC 1995”), with relevant sections 40 and 41 of the draft Incapable Adults (Scotland) Bill appended to that Report (“SLC draft Bill”). Those sections are reproduced in Appendix C to Annex A. That draft Bill subsequently became substantially the Adults with Incapacity (Scotland) Act 2000 (“2000 Act”). Proposed sections 40 and 41 were however omitted, on the basis that the existing law was uncertain and the courts could be expected to develop it. They have not done so. Meanwhile, relevant law in England & Wales has been clarified with the Mental Capacity Act 2005 (“2005 Act”). Scots law is now less clear than the law of England & Wales. This is particularly the case in respect of medical practitioners, who are protected from prosecution and from civil liability in England & Wales if they comply with relevant requirements<sup>3</sup>, but do not have similar statutory protection in Scotland<sup>4</sup>. On the contrary, persons acting under the medical treatment and research provisions of Part 5 of the 2000 Act are specifically excluded from the limitation of liability provisions of section 82 of that Act<sup>5</sup>.

We stressed the importance of revisiting and addressing the “missing provisions” from the 2000 Act in our response to the Scottish Government’s 2018 consultation on AWI reform<sup>6</sup>. Temporary modifications to this effect were suggested in our letter to the Cabinet Secretary for Health and Sport dated 15 April 2020<sup>7</sup>. We are not aware of any current plans for temporary or lasting reform in this area. It has been identified by practitioners, both legal and medical, as an area where the current law is deficient, and reform is required.

An underlying source of much confusion and uncertainty is the frequency with which propositions and advice based on English law, in matters where Scots law is different, are promulgated in Scotland without acknowledgement of the difference between the two legal systems. Again, this is an issue of long standing, but was exacerbated and made more visible during the pandemic, with (for example) encouragement to make advance directives apparently based upon the status accorded to them in English law, but not in Scots law.

3 2005 Act, section 5.

4 See Reporting Deaths to the Procurator Fiscal - Information and Guidance for Medical Practitioners (Crown Office and Procurator Fiscal Service, 2015), para. 13.

5 Section 82(1) of the 2000 Act provides that no liability is incurred by guardians, attorneys, persons authorised under intervention orders, withdrawers or managers of establishments (that is to say, appointees under Parts 2, 3, 4 and 6 of the 2000 Act) for acting or not acting in good faith and in accordance with the general principles in section 1 of the 2000 Act.

6 <https://www.lawscot.org.uk/media/360115/18-04-30-mhd-consultation-awi-reform.pdf>.

7 <https://www.lawscot.org.uk/news-and-events/legal-news/ministers-urged-to-reform-awi-law-for-covid-19-cases/>.

This paper is published in the context of the separate but ongoing Scottish Mental Health Law Review (“SMHLR”), due to submit its Final Report in the latter part of 2022. We hope that this paper will help inform the work of the Review insofar as it relates to matters within the scope of the Review.

Human rights considerations must be central to any discussion of, and proposals for reform of, the law relating to advance choices and medical decision-making in intensive care. Discussion of international human rights obligations, and the extent to which Scots law is compliant with these obligations, is set out in relevant sections of this paper.

At the time of finalising this paper the litigation between PKM’s guardians and Greater Glasgow Health Board<sup>8</sup>, which raises important issues regarding medical decision-making and the status of DNACPR forms, remains live. The final outcome of this case may also inform further debate regarding the need for reform.

<sup>8</sup> PKM’s guardians raised two actions against Greater Glasgow Health Board. Both sought orders under section 70(1)(a) of the 2000 Act. The first action concerned a refusal by the adult PKM of certain medical treatment. The second concerned agreement by the adult that a DNACPR notice be placed in his records. Medical practitioners had assessed that the decisions by the adult in both matters had been competent. The guardians sought to overrule those decisions of the adult. In the first action the guardians were successful before the Sheriff Appeal Court (2021) SAC (Civ) 33. SAC acceded to a request that an appeal against an interim order in the second action be remitted to the Inner House of the Court of Session, because it raised the same key issue in law as had been determined by SAC in the first action. The Inner House determined that appeal on 16 December 2021, on narrow consideration of whether the sheriff at first instance was entitled to make the interim order, and without at that stage addressing the key issues in the litigation. The Inner House issued a Statement of Reasons which at time of writing remains unreported. The second action returned to Dumbarton Sheriff Court. Mental Welfare Commission entered the process. At time of finalisation of this paper, the second action remained outstanding.

## PROJECT WORK

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To support the Project, we established a Working Group of expert volunteers drawn from legal practice and academia<sup>9</sup>. The Annexes to this paper include papers contributed by various members of the Working Group, largely comprising the research and other material, on the basis of which the Working Group proceeded with the deliberations resulting in the conclusions and recommendations set out in this paper.

At an early stage of its work, the Working Group recognised that aspects (a) and (b) of the Project objective 1 set out above were distinctive topics that nevertheless overlapped. To an extent, the Working Group resolved to address them separately, but – in addressing each – to have close regard to its developing work in relation to the other. After dealing with matters common to both topics, this paper proceeds to address them separately, before drawing them back together in the Recommendations.

Five research questions guided the project work:

1. What human rights principles are involved?
2. What ethical considerations need to be addressed?
3. What is the relevant existing Scots law on all matters within our remit?
4. What can we learn from relevant law, developments and experience in England & Wales and elsewhere, including from the background to such developments?
5. What are the existing proposals for reform, clarification or creation of Scots law, and what is the background from which they have been developed? What is our evaluation of them?

The paper on “Advance directives” reproduced as Annex A suggested further research questions derived principally from Rec.(2009)11, CRPD, and the work of HCCH. These were reviewed and refined to produce the questions set out in Annex B as they formed the basis of the Working Group’s deliberations in relation to advance choices. The outcome of those deliberations appears in the recommendations (insofar as relevant to advance choices) in this paper. An account of those deliberations, including the reasons for the resulting recommendations, is set out in Annex B. Other jurisdictions contemplating the introduction of advance choices (advance directives), or development of existing provision for them, might find it useful to refer to the Working Group’s analysis of questions to be addressed. The reasons for the Working Group’s answers might also be of interest, though of course answers to the same questions in different jurisdictions might vary.

<sup>9</sup> An English practitioner, a member of the equivalent committees of the Law Societies of both Scotland and England & Wales, contributed comparative information and evaluation.

## 5. Advance choices

### 5.1 Scope and terminology

For the purposes of the Project, we have adopted the broad definition of the potential scope of advance choices contained in Principles 2.3 and 14 of Rec. (2009)11, from which we derived this definition:

*“Instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity, and which may apply to all or any of health, welfare and other personal matters, to economic and financial matters, and to any juridical act<sup>10</sup> not expressly excluded by law from the potential scope of advance instructions given in an advance choice”*

Principles 2.3 and 14 of Rec. (2009)11 are quoted, with commentary, in Annex A.

We adopt the broad scope and categorisations of advance directives in Rec. (2009)11, but not the terminology. Terminology employed must be widely understood, and correctly used and applied. In particular, the language used must be clear and accessible. The scope for misunderstanding and misuse is considerable. One need only point to frequent confusion in Scotland between “powers of attorney” and “guardianship,” and use of “powers of attorney” to mean both the document and the person appointed under it. Confusion and misunderstanding can be caused by failures to distinguish between English and Scottish terminologies, and their respective consequences.

With one exception, there is no existing relevant terminology in Scots law, because (with that one exception) there is no existing statutory provision in Scots law for advance choices of any kind. The exception is for “advance statements” under the 2003 Act, which for clarity we refer to as “*mental health advance statements*”.

In 1995 the Scottish Law Commission proposed provision for *medical advance choices* (termed by the Commission “advance statements”<sup>11</sup>). In other personal welfare matters, and in property, financial and economic matters, there is no statutory provision in Scotland for advance choices, nor have there been proposals for such provision, except that the requirement of section 1(4)(a) of the 2000 Act to have regard to “the past wishes and feelings” of the adult could reasonably be seen as bringing any statement of wishes and feelings within the scope of advance statements<sup>12</sup>.

There is no statutory provision, nor have there been proposals, for advance instructions.

A key purpose of this paper is to promote the filling of those substantial gaps. It is in the public interest that the gaps be filled. The place of advance choices in the human rights landscape, and the human rights imperatives towards making them available to citizens where they are not, are explored in the next section

<sup>10</sup> “Juridical acts” are defined in the “Abbreviations and definitions” section above.

<sup>11</sup> The provisions proposed by the Commission are quoted at Appendix C to Annex A.

<sup>12</sup> As noted below, unlike the position in England & Wales, section 1(4)(a) gives no enhanced status to wishes and feelings expressed in writing.

(section 5.2). Examples of the uses to which advance choices might be used are then provided in the ensuing section (section 5.3).

Presenting the structure that we propose diagrammatically, firstly, the structure and terminology in Rec. (2009)11 is as follows:

Diagram A (per Rec. (2009)11)

- Advance Directives
- Instructions given
  - Wishes made

Translated into the more accurate and accessible terminology that we propose, Diagram A reads as follows:

Diagram B (Accessible Terminology used and recommended in this paper)

**ADVANCE CHOICE**

- **ADVANCE INSTRUCTIONS** (= instructions given)
- **ADVANCE STATEMENT** (= wishes made)

We have already noted the separate concepts of medical advance choices, and mental health advance statements. Later in this paper, we introduce the concept of the “top-level” advance choice. Adding these to the structure of Diagrams A and B, with the terminology that we propose, gives the following:

Diagram C (Accessible Terminology used and recommended in this paper)

**ADVANCE CHOICE**

- **ADVANCE INSTRUCTIONS** (= instructions given)
  - o **TOP-LEVEL** (see section 5.4 below)
  - o Medical advance instructions
  - o Other Advance instructions
- **ADVANCE STATEMENT** (= wishes made)
  - o **TOP-LEVEL** (see section 5.4 below)
  - o Medical advance statement
  - o Mental health advance statement
  - o Other advance statements

In the above diagram, “medical advance instructions” are medical advance choices giving instructions rather than making wishes; and “medical advance statement” is a medical advance choice making wishes rather than giving instructions.

All of the categories of advance choice in Diagram C (including top-level advance instructions and advance statements) may apply to all or any of health, welfare and other personal matters, to economic and financial matters, and to any juridical act (see abbreviations and definitions section) not expressly excluded by law from the potential scope of advance instructions given in an advance choice, with the exception of the limitation to medical matters of medical advance instructions and medical advance statements, and the further limitation to mental health matters of mental health advance statements.

The terminology in Diagram C is the terminology adopted for this paper, and which we recommend for implementation of our proposals<sup>13</sup>.

Advance choices are the first of the two topics addressed by the Project. Medical advance choices and mental health advance statements are however integral to the second topic, that of medical decision-making. They represent the area of “overlap” between the two topics, and the reason why neither can reasonably be considered and addressed without taking account of the other. In this paper, matters generally relevant to all advance choices are dealt with under “advance choices”, but aspects particular to the medical sphere are dealt with under “medical decision-making”. Note also that such case law as has been developed relates entirely to medical advance choices, but in general terms may reasonably be seen as stating the current position in law (in the absence of legislative provision) of all advance choices.

## 5.2 Human rights and international instruments

Over a period of several years, jurisprudence, both generally and medico-legal jurisprudence, has increasingly moved away from a more paternalistic approach to recognition of the importance of autonomy. That has been a clear trend internationally, and particularly in Scotland. In parallel, there has already been a clear shift in the basic concept of disabilities (including mental, intellectual and sensory disabilities) from a medical model to a social model, followed by a current shift towards a human rights model. CRPD underlines the shift to a social model, and paves the way towards full adoption of a human rights model. Information in the public domain on the developing work of the SMHLR also indicates the likely adoption of a predominantly human rights model in Scotland. The recommendations in this paper are designed to be consistent with that approach, and to support it.

Also of particular relevance to Scotland has been the work of the Council of Europe on advance choices (“advance directives”). Relevant Council of Europe Recommendations indicate that priority should be given to rights to autonomy and self-determination, so that voluntary measures established by an adult should be preferred to non-voluntary measures created otherwise than by adults themselves.

Relevant Council of Europe Recommendations have developed from urging states to consider providing for voluntary measures, to requiring them to promote self-determination by means of both powers of attorney and advance choices. See Annex A for relevant provisions and commentary on them.

Of key importance to the topic of advance choices is the CoE 2018 Report. The findings and recommendations in the report, insofar as relevant to advance choices, are in Appendix A to Annex A.

<sup>13</sup> Note however that that terminology was adopted only after the papers reproduced in the Annexes were written.

Briefly, the review reported considerable progress across Europe in provision of powers of attorney and their use, with development of advance directives following well behind. International aspects generally, and those derived from Council of Europe in particular, are narrated in Annex A, which contains in Appendix A all of the findings and recommendations relevant to “advance directives” in the review of implementation of Rec.(2009)11.

Standing behind Council of Europe Recommendations are of course the requirements of the European Convention on Human Rights. Of particular relevance are the provisions of:

- Article 2 - right to life
- Article 3 - prohibition of torture and inhuman or degrading treatment
- Article 5 - right to liberty and security
- Article 8 - right to family and private life, and in particular the principle of personal autonomy
- Article 14 - prohibition on discrimination

CRPD rights are also relevant, particularly Article 12, the right to equal legal recognition before the law. The maximum facilitation of effective exercise of legal capacity by adults themselves is central to the implementation of CRPD, and the availability and use of advance choices is an essential component of achieving that. There is ongoing political and legal discussion and consideration as to the precise meaning of CRPD, and as to the extent CRPD rights should be incorporated into Scots law. The Scottish Government has committed to incorporating, as far as possible within devolved competence, CRPD into Scots law as part of a new Human Rights Bill expected to be introduced in the current parliamentary session<sup>14</sup>. The conclusions and recommendations in this paper have been directed by reference to the principles of Article 12, although not necessarily to the interpretation of it given by the UN Committee on the Rights of Persons with Disabilities in General Comment 1 to Article 12<sup>15</sup>.

As regards the foregoing references to voluntary and non-voluntary measures, former terminology referring to anticipatory, responsive and third party measures has been generally superseded by the following:

Diagram D (Modern “Technical Terminology”)

Measures

- Voluntary Measures
  - o Unilateral
  - o Bilateral
- Non-Voluntary Measures
- Third Party Measures

<sup>14</sup> See: New Human Rights Bill - gov.scot (www.gov.scot) (12 March 2021) and A Fairer, Greener Scotland: Programme for Government 2021-22 - gov.scot (www.gov.scot) (7 September 2021) at page 49.

<sup>15</sup> CRPD/C/GC/1.

In light of the foregoing, as expanded in Annex A, it is our clear view that Scots law at present fails to comply with human rights obligations in respect that it contains no clear and adequate provision for advance choices, and that Scottish Government is accordingly under an obligation to make such provision.

### **5.3 Practical utility of advance choices**

Beyond existing scope (and some provision) for use of advance choices in relation to medical matters, citizens can be expected to make increasing and substantial use of advance choices if provision for them becomes available and is suitably publicised. That can be expected to apply to both “instructions given” and “wishes made” advance choices (that is to say, to both advance instructions and advance statements). For a selection of examples of ways in which they would be used in relation to property, financial and economic matters, and to personal welfare and other matters beyond the medical sphere, see paragraphs 4.6 – 4.9 of the paper reproduced as Annex A.

### **5.4 Fundamental concepts**

We consider the following topics to be of particular relevance to the concept of advance choices as measures supportive above all of exercise of rights to autonomy and self-determination.

Firstly, there is a tension between maximum availability of such measures, pointing towards the minimum of formality, but also the need to safeguard certainty and to avoid potential vitiating factors<sup>16</sup>. We would suggest that the best solution is a range of requirements providing corresponding degrees of certainty and protection. That range, up to and including “top level”, would apply both to advance instructions and to advance wishes. At the most informal end, no-one should be disqualified from setting out their wishes for the future, in the form of a very simple advance statement. At the other end of the scale, there should be a “top-level” advance choice offering significant protection and safeguards, resulting in a high level of certainty and operability, and, in the case of advance instructions, the lowest risk of disapplication in any particular circumstances. Among other things, this approach facilitates maximum use of advance choices, and accessibility for the maximum range of people in the maximum range of circumstances.

Linked to the foregoing, secondly, are the issues raised by the fundamental characteristic of advance choices, namely that they are created at one point in time but become operable some time later, when considerations have emerged that might have influenced the granter at time of creation, but the granter either did not review the advance choice and/or may have no longer been capable of doing so. Put another way, on the one hand, provision for advance choices offers the opportunity for citizens to determine, or at least influence, future outcomes; but on the other hand, the time lag between creation of the advance choice and its potential operation can present challenges. We would suggest that an advance choice should not be treated as revoked by a change in circumstances – rather, the question might need to be addressed as to whether the advance choice should be disapplied from the matter and in the circumstances that have actually arisen. We have considered what should be the criteria for disapplication at section 8.4 below.

<sup>16</sup> That includes the need to ensure the safeguards required by Article 12.4 of CRPD.

Aspects of medical advance choices which are unique to that category are generally addressed in the next section.

## 5.5 Comparative analysis

There are fundamental differences in relevant areas of law between Scotland, and England & Wales, contributing to the lack of clarity as to Scots law. The applicable law in England & Wales is the 2005 Act. This legislation turns on assessment of the 'best interests' of the incapable adult, rather than their 'will' (actual or constructed), and for that reason caution must be exercised in assuming that the approach adopted by the courts in England & Wales would be adopted in Scotland.

In England & Wales, advance choices to refuse medical treatment (termed 'advance decisions') are recognised as legally binding, subject to certain procedural requirements and exceptions set out in the 2005 Act. The 2005 Act gives particular status to wishes and feelings recorded in writing (section 4(6)).

The operation of advance decisions in England & Wales has illustrated a number of areas where dilemmas may arise in the operation of a legislative scheme for advance choices:

- Creation - there is a tension between formality and accessibility. A higher level of formality may make an advance choice less susceptible to challenge, but may also make it more difficult to grant and therefore less accessible. Linked to this is the issue of authentication- certification of capacity of the person to create the document, and separately authenticating or otherwise confirming that the advance choice has been produced without undue influence. The 2005 Act does not require any 'authentication' in relation to advance decisions to refuse treatment, and this has created practical problems<sup>17</sup>.
- The period between creation and the intended circumstances arising - creation of an advance choice document immediately creates a practical issue of where and how the document should be stored. Provision should be made in legislation for circumstances where an advance choice has been made, but has not been recorded in the relevant medical or other records. English case law has also highlighted the difficulties which may arise where an advance choice is made but not revisited for many years<sup>18</sup>. This raises questions about how much weight should be given to a very old advance choice which has not been reviewed.
- Consequence when the intended circumstances arise - traditionally, advance choices have taken effect on loss of capacity, as opposed to operating on an entirely self-directed basis. However, this approach creates tensions with CRPD, and specifically with the comments of the Committee on the Rights of Persons with Disabilities set out in General Comment 1 to Article 12<sup>19</sup>, which states that the point at which the advance choice enters into force should be self-directed<sup>20</sup>. Linked to this is the question of whether, and in what circumstances, it is legitimate not to follow an advance choice. The Committee on the Rights of Persons with Disabilities has indicated that this should be possible only where the granter

<sup>17</sup> See, for example, *Re E (Medical treatment: Anorexia)* [2012] EWCOP 1639.

<sup>18</sup> See, for example, *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52.

<sup>19</sup> CRPD/C/GC/1.

<sup>20</sup> General Comment 1 paragraph 17 asserts that "The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity."

has so provided, but this approach has practical difficulties, including those linked to formality and noted above. The approach advocated by the Committee is fundamentally incompatible with the governing legal frameworks for health and social care in Scotland, and any proposed change in that regard would raise fundamental ethical considerations which would require law reform beyond the scope of the remit of the Project.

A comparative analysis of the differences in the relevant areas of law between Scotland, and England & Wales is set out within the literature review at Annex C, and is further addressed in Annex D. In Scots law, all interventions under the 2000 Act require to comply with principles set out in section 1. Those principles point the way towards how advance choices should be treated, but there is no express provision for advance choices anywhere in existing Scots law, except for the provisions in the 2003 Act limited to mental health advance statements. Section 1(4)(a) of the 2000 Act requires that in determining whether to intervene, and if so what intervention should be made, whoever is responsible for making or authorising the intervention must take account of “the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication ... appropriate to the adult”. The importance of this is emphasised in that the list of other persons whose views should be taken into account are all qualified “in so far as it is reasonable and practicable to do so”, but that limitation does not apply to the adult. Thus, a statement of “past wishes and feelings” in an advance choice would have to be taken into account. Although the precise meaning of the requirement to respect the rights, will and preferences of the person under CRPD Article 12 is not entirely settled, it would appear to require more than simply acknowledging a person’s past wishes, especially where they have sought to record those wishes in a fashion they intend to be determinative.

It is also useful to consider the legal position in other comparable jurisdictions, particularly Germany (and, prospectively, France and Spain). Germany has developed rules which govern the lawfulness of interventions in the affairs of an incapable adult. It can be argued that these rules are modelled on the doctrine of *negotiorum gestio* (see section 6.5, below), and strongly correlate with the present position in Scots law. Further detail is set out at Annex C.

The German courts have found that CRPD mandates that the legislature devise methodology to allow for the ‘construction’ of a person’s ‘will’ where that individual’s ‘free will’ cannot be identified. The German approach suggests some correlation between Scots and German law.

Germany has gone further than Scotland, in that it has integrated rules on ‘living wills’ alongside the basic doctrine of *negotiorum gestio* and rules on ‘presumed consent’ in the context of medical treatment. A ‘living will’ in Germany is treated as a binding expression of individual autonomy where it is validly constituted. If there is no validly constituted ‘living will’, it is necessary to attempt to determine the wishes of the person (not what is in their ‘best interests’). However, the German courts have encountered difficulties in applying the relevant legislation. On the fundamental difference in approach to the concept of “best interests” as between England & Wales (where it was adopted for adults) and Scotland (where it was rejected) see

*“With and without ‘best interests’: the Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and Constructing Decisions”<sup>21</sup>.*

The experience in Germany and also in England & Wales demonstrates one of the primary difficulties with the concept of binding advance choices - the extent to which they are held to continue to be binding if the incapacitated person demonstrates that they no longer wish to be bound by the terms of the instruction which they issued while competent. In the medical sphere, this in turn demonstrates the importance of integrating the creation of binding instruments with the more general practice of medicine.

## 6. Medical decision-making

The full title of this second topic within the scope of the Project is “Medical decision-making in intensive care situations, including decisions about refusing or withdrawing life-sustaining treatment”.

### 6.1 Ethical considerations

We recognise that the medical issues addressed in this paper raise complex ethical considerations, alongside legal issues. A full analysis of the relevant ethical considerations, and the background of practice issues encountered by medical professionals working in this area, is beyond the scope of this paper. However, we recognise that any proposals for law reform in this area must effectively integrate the creation of instruments potentially binding upon doctors and other relevant professionals within the more general practice of medicine. We also recognise the role of the GMC in regulating the conduct of medical practitioners throughout the UK.

An analysis of the ethical considerations which need to be addressed when dealing with advance care planning and medical decision-making in an ICU is included at Annex E.

### 6.2 The relevant existing Scots law

There is a lack of clarity in Scots law as it relates to medical advance choices and medical decision-making in intensive care situations.

The Scottish Law Commission Discussion Paper No 94 on Mentally Disabled Adults (September 1991) emphasised (in paragraph 3.4) that: “The starting point is that persons of full capacity are entitled to decide what treatment, if any, they will have. The invasion of a person’s bodily integrity by treatment that he or she has not consented to (or that has not otherwise been authorised) amounts to a criminal offence and a civil wrong.” (with reference to dicta by Lord Reid in *S v S*<sup>22</sup> and *W v Official Solicitor*<sup>23</sup>). Those dicta clearly apply both to consideration of the operation of medical advance choices and to medical decision-making in ICU situations. How this applies in daily practice highlights the lack of clarity for practitioners and patients

<sup>21</sup> By Alex Ruck Keene and Adrian D Ward, [2016] International Journal of Mental Health and Capacity Law at: <https://www.northumbriajournals.co.uk/index.php/ijmhcl/article/view/549>. On concepts of “will”, and comparison of German law and Scots law, see “Respecting ‘will’: Viscount Stair and online shopping”, 2018 SLT (News) 123, particularly at pages 125-126.

<sup>22</sup> *S v S* [1970] 3 All ER 107 (per Lord Reid at p111).

<sup>23</sup> *W v Official Solicitor* [1972] AC 24 (per Lord Reid at p43).

alike when considered in the light of recent decisions of the court (or lack of them) and the statutory framework now in place to reflect more recently acknowledged rights of patients in understanding what they are consenting to by way of treatment when they have capacity to do so.

### 6.3 Providing treatment to “adults with incapacity”

The position in relation to adults with impairments of their relevant capabilities is more complicated. The 2000 Act provides a legislative framework for decision-making on behalf of such adults. Part 5 relates to medical treatment and research. Under Part 5, medical treatment to ‘safeguard or promote the physical or mental health of the adult’ can be provided, subject to various procedural safeguards, where the adult is incapable in relation to a decision about the medical treatment in question.

### 6.4 Withdrawal of treatment

Scottish physicians do not, as doctors in the rest of the UK might do, have the power ‘to unilaterally withdraw or withhold treatment that they regard to be futile’<sup>24</sup>. Part 5 does not operate to allow withdrawal of treatment to operate in this way. Rather, the Court of Session stands as *parens patriae* in respect of the patient and must, in disputed cases, ‘step into the shoes of’ the patient or their parent and act as surrogate decision-maker”. In the 1996 case of *Law Hospital NHS Trust v Lord Advocate*<sup>25</sup>, the Court of Session held that the withdrawal of artificial hydration, nutrition or non-palliative treatment may be in the ‘best interests’ of a patient in a permanent vegetative state, and that in recognition of this fact consent to such withdrawal, by the Court on behalf of the patient, could be given ‘with the same effect in law as if consent [to the withdrawal of treatment] had been given by the patient [themselves]’<sup>26</sup>. Such consent may be sufficient to safeguard the attending physicians from civil lawsuit. In the case of *Law Hospital* itself, although it was argued that a declarator would not generally be appropriate, the Lord Ordinary made a declarator. This was to the effect that withdrawing treatment in that particular case would not be unlawful insofar as Scots civil law was concerned. However the Court of Session ultimately held that it did not have the vires to rule on matters of Scots criminal law. As such, it fell to the then Lord Advocate to issue prosecutorial guidance<sup>27</sup>. The original guidance is reproduced at the end of the reports of the *Law Hospital* case. The Lord Advocate intimated that he had decided that he would not authorise the prosecution of a qualified medical practitioner (or any person acting upon the instructions of such practitioner) who, acting in good faith and with the authority of the Court of Session, withdraws or otherwise causes to be discontinued life-sustaining treatment or other medical treatment from a patient in a persistent, or permanent, vegetative state, with the result that the patient dies. The latest formulation of the guidance is to be found at: [REPORTING DEATHS TO THE PROCURATOR FISCAL \(copfs.gov.uk\)](https://www.copfs.gov.uk/reports-and-guidance/reports-and-guidance-reports/reports-and-guidance-reports-2017-2018/reports-and-guidance-reports-2017-2018-2018-2019).

24 Eliana Close, Lindy Willmott and Benjamin P White, Charlie Gard: In Defence of the Law, (2018) 44 *Journal of Medical Ethics* 476, 476–7, though it is acknowledged that this reference relates to children. However, in relation to adults the Supreme Court has made it clear that no-one can demand a treatment which the doctors do not consider appropriate: *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at paragraph 18, which is generally understood to be the law in Scotland, an issue which arose in the first case in the PKM litigation (see footnote 8).

25 1996 SC 301.

26 *Ibid* at 315 per Lord President Hope.

27 See also Lord MacKay of Drumadoon, Decision on the Persistent Vegetative State: *Law Hospital* (1996) Paper presented at the Symposium on Medical Ethics and Legal Medicine, Royal College of Physicians and Surgeons of Glasgow, 26th April 1996.

As the editors of *Mason & McCall Smith's Law and Medical Ethics* have observed, 'both the Lord President and the Lord Advocate of the time agreed that decisions could be made on medical grounds and independently of the courts – but neither gave any guidance as to when it would be either necessary or unnecessary to seek judicial approval'<sup>28</sup>. Since 1996, there have been no reported Scottish cases concerning withdrawal of treatment from incapable (adult or child) patients. The law pertaining to withdrawing medical treatment in Scotland, then, remains 'indefensibly vague'.

While the *PKM's Guardians* litigation (see footnote 8) deals with a different kind of withdrawal from treatment situation in the context of consent by the patient but opposition by the guardian, it may provide more guidance on the current law.

The last significant change to Scots law as it relates to the withdrawal of medical treatment from incapable adults might be said to have occurred – indirectly – with the passing of the 2000 Act. Although the then Scottish Executive ostensibly sought to keep 'negative treatment' outwith the remit of the legislation, in practice 'it is impossible to maintain a clear distinction between positive and negative treatment decisions involving incapable adults'<sup>29</sup>. Thus, the principles which underpin the 2000 Act may now have a bearing on the decision-making process in cases involving the withdrawal of medical treatment as well as in cases of proposed positive intervention. Prior to the introduction of the 2000 Act, determining whether or not treatment should be withdrawn was – as in cases concerning the withdrawal of treatment from infants<sup>30</sup> – in the adult's 'best interests', but with the passing of the 2000 Act the ultimate decision-maker (i.e., either the attending physicians or, if the case is controverted, the Court of Session) must ask "do we know or can we find out what the patient would want done under the circumstances at hand?" not, "what do we think is 'best' for the patient?"<sup>31</sup>. While best interests generally remains the test for children, it was rejected for adults in terms of SLC 1995 in favour of the principles proposed in the SLC draft Bill, which appeared unamended in section 1 of the 2000 Act and have been adopted for other purposes<sup>32</sup>. Where medical practitioners make decisions within the scope of the 2000 Act, they must comply with the section 1 principles, rather than adopting a best interests test. The approach of the 2000 Act is generally accepted as the proper basis for all decision-making and other interventions in relation to adults with impairments of relevant capabilities. If there is evidence to suggest that the patient would consent to the withdrawal of treatment, then this withdrawal can be effected without civil law consequence (although the position of the criminal law remains unclear, and without authorisation from the Court of Session the possibility of a prosecution remains open), but if there is no such evidence, or evidence to the contrary, then the withdrawal of treatment will be civilly unlawful as well as potentially criminal. The principles of *negotiorum*

28 G. T. Laurie, S. H. E. Harmon and E. S. Dove, *Mason and McCall Smith's Law and Medical Ethics*, (11th Edn.) (Oxford University Press, 2019), para.16.124.

29 Scottish Executive Policy Memorandum 8th October 1999.

30 Of which, see Jonathan Brown and Sarah Christie, *Pater Knows Best: Withdrawal of Medical Treatment from Infants in Scotland*, [2020] OJLS 682, *passim*.

31 David W. Meyers, 'T B Smith: a Pioneer of Modern Medical Jurisprudence', in Elspeth C. Reid and David L. Carey Miller, *A Mixed Legal System in Transition: T. B. Smith and the Progress of Scots Law*, (Edinburgh University Press, 2005), at 209.

32 Scottish Law Commission's reasons appear in paragraph 2.50 of SLC 1995.

*gestio* would however suggest that the intervenor who acts on the basis of the reasonable belief that the *dominus* would have consented will incur no liability<sup>33</sup>.

## 6.5 Common law

It can be argued that the 2000 Act suggests a movement towards a *negotiorum gestio* [literally 'management of affairs', but more accurately translated as 'benevolent intervention'] model for any medical decision-making where – for any reason – the patient is not (at the time when the decision needs to be made) able competently to accept or refuse proposed treatment, consistent with the underlying framework of Scots common law. *Negotiorum gestio* is a core element of Scots private law<sup>34</sup> and can be defined as 'the voluntary management by one person (the *negotiorum gestor* [i.e., the intervenor]) of the affairs of another (the *dominus negotii* [i.e., the principal]) without the consent or even the knowledge of the other'<sup>35</sup>. *Per Bell*, the management of affairs must be undertaken 'on the presumption that the [principal] would, if aware of the circumstances, have given a mandate for such interference';<sup>36</sup> in other words, the intervenor must act in the reasonable belief that the principal would have consented to the intervention had they been capable of doing so. If a true relationship of *negotiorum gestio* is constituted, then the intervenor has a defence to any claim of delictual liability<sup>37</sup>, provided that they did not culpably cause loss to the principal in the course of their intervention<sup>38</sup>.

The Scottish Law Commission noted in SLC 1995 that the law on *negotiorum gestio* was an element of Scots common law which might be usefully invoked to enable action to be taken where an adult is incapable of taking decisions or acting for themselves<sup>39</sup>. However, it was recognised that Scots law had not at that time expressly extended the doctrine to cover healthcare matters<sup>40</sup>. Even as of today 'it has not yet been resolved whether intervention within the scope of *negotiorum gestio* may only consist of a juridical act for the benefit of a person's assets, or whether it might also consist of acts to save the health or life of another. There are as of yet no reported judicial decisions indicating that an intervention rendering such aid to a person in an emergency is within the scope of the law of benevolent intervention, but equally there seems to be no decision explicitly to the contrary'<sup>41</sup>. It should, however, be noted that in Denmark, which has a law of *negotiorum gestio* which is 'similar' to that of Scotland, 'it seems to be regarded as self-evident that acts of benevolent intervention may be directed towards saving the life and preserving the health of another'<sup>42</sup>.

33 In Scots law as it stands, that suggestion is reliant on the *negotiorum gestio* view being favoured as a descriptive account of how the law presently operates (other views may, of course, be taken).

34 See Scotland Act 1998, s.126 (4).

35 Stair Memorial Encyclopaedia, Obligations, (Vol.15) para.87.

36 Bell Principles, s.540; see also *A S Kolbin & Sons v William Kinnear & Co* 1930 SC 724 at 752 per Lord Ormidale.

37 See Annex C.

38 SME, Obligations, (Vol.15) para.90. The standard of care expected of the gestor is the same as the requisite delictual standard of care; that is, the gestor is bound to take reasonable care in the circumstances : *A S Kolbin & Sons v William Kinnear & Co* 1930 SC 724.

39 Scottish Law Commission, Report on Vulnerable Adults (Scot. Law Com. No. 151), para.1.7.

40 Stair Memorial Encyclopaedia, Obligations, (Vol.15) para.102.

41 Christian von Bar, Benevolent Intervention in Another's Affairs,(Bruylant, 2009), at 74.

42 Christian von Bar, Benevolent Intervention in Another's Affairs,(Bruylant, 2009), at 74.

While, then, it is likely the case that most lawyers, never mind medical practitioners, are unaware that they are potentially entering the area of the law of *negotiorum gestio*, in Scotland (although it has been noted that in certain civil law jurisdictions the ‘institution may appear familiar to some medical doctors’)<sup>43</sup>, there can be little doubt that ‘in broad terms, *negotiorum gestio*-like actions have played a considerable role in health care provision’ within jurisdictions which possess a comparable framework of private law<sup>44</sup>. Indeed, as is discussed in the literature review at Annex C, the law relating to *negotiorum gestio* provides a pre-existing formulation of an appropriate approach to identifying and applying the ‘best interpretation’ of an adult’s will and preferences in terms of General Comment 1 to CRPD.

Although there is literature to suggest that *negotiorum gestio* is a useful concept which could be developed further to more clearly apply in this area, the lack of litigation in medico-legal matters in Scotland may indicate that the courts are not best placed to develop the law pertaining to the concept, and that legislative reform is required to clarify the position in relation both to medical advance choices, and to medical decision-making more generally.

A full literature review of the current position in Scots law is included at Annex C.

## 6.6 Decision-making in intensive care situations

There is little specific legislation or case law around medical decision-making in ICUs in Scotland beyond what has been established by medical negligence case law, reflecting developing knowledge and technology and as set out in guidance from the GMC. While Annex E discusses advance care planning and medical decision-making, we do not attempt a comprehensive analysis of where such decision-making sits in Scots law today, it being a very fact-specific area of law. However we note the approach taken by the Supreme Court in *Montgomery v Lanarkshire Health Board*<sup>45</sup>, where the court effectively applied the standard of the GMC at the relevant time to the facts of the case. While that case dealt with informed consent within the context of negligence, it seems not unreasonable to anticipate a similar approach to ‘real-time’ decision-making in treatment, planning and decision-making in ICU in relation to patients incapable of giving or declining consent.

## 6.7 Previous proposals for reform, clarification or creation of Scots law, and evaluation

The topics of medical advance choices (therein termed ‘advance statements’), and of refusal or withdrawal of life-sustaining treatment, were addressed in Scottish Law Commission Report No 151 on Incapable Adults (September 1995) (“SLC 1995”), with relevant sections 40 and 41 of the draft Incapable Adults (Scotland) Bill appended to that Report (“SLC Draft Bill”). Those sections are reproduced in Appendix C to Annex A.

43 Søren Birkeland, *Negotiorum Gestio in Family Medicine, Informed Consent Obtainment and Disciplinary Responsibility*, [2016] *International Journal of Family Medicine* 1, at 1.

44 Søren Birkeland, *Negotiorum Gestio in Family Medicine, Informed Consent Obtainment and Disciplinary Responsibility*, [2016] *International Journal of Family Medicine* 1.

45 [2015] UKSC 11.

As noted above, the draft Bill subsequently became substantially the 2000 Act but sections 40 and 41 of the SLC draft Bill were omitted. They remain, however, the most recent proposals for reform, clarification or creation of Scots law in the area of medical advance choices and medical decision-making. Comments on the unimplemented sections 40 and 41 of the SLC draft Bill are set out in Annexes A and F.

## RECOMMENDATIONS

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**Note:** All of the following recommendations relate to either or both of the two topics within the remit of the project, namely:

- (a) the topic of advance choices; and
- (b) the topic of medical decision-making in intensive care situations, including decisions about refusing or withdrawing life-sustaining treatment (all of which is for convenience referred to in these recommendations as “medical decision-making”).

Those two topics are referred together as “the topics”. Both topics fall within the devolved competence of the Scottish Parliament.

### 7. Legislative provision

- (1) In respect that in Scots law there is at present no clear and comprehensive legislative provision for either of the topics, our primary recommendation is that the Scottish Parliament should legislate to make clear and comprehensive legislative provision for each of the topics.
- (2) To be readily accessible to all who might require to refer to it, the legislative provision for each topic should as far as possible form discrete new Parts either in existing legislation, or in any new legislative scheme following upon the proposals of the SMHLR. If added to existing legislation, the topic of advance choices could form a new Part 2A of the 2000 Act, following immediately after Part 2 of that Act (“Continuing powers of attorney and welfare powers of attorney”); and the topic of medical decision-making could form a new Part 5A immediately after Part 5 (“Medical treatment and research”).
- (3) Legislative provision for advance choices should have the objective of providing clarity and certainty for all who might wish to create advance choices, and for all who might be required to follow the instructions in advance choices, or to have regard to wishes made in advance choices, as well as those involved professionally or otherwise in the provision of relevant services, or with relevant management, administrative or judicial roles.
- (4) Legislative provision for medical decision-making should have the objective of providing clarity and certainty for patients who might be the subject of medical decision-making, including those wishing to make anticipatory provision, and for professionals and others who might be required to engage or participate in medical decision-making, or implement such decision-making, and should have the objective of providing clarity and certainty for all who might wish to create advance choices and all who might be required to follow the instructions in advance choices, or to have regard to wishes made in advance choices, as well as those involved professionally or otherwise in the provision of relevant services, or with relevant management, administrative or judicial roles.

- (5) Legislative provision should provide safeguards to ensure that persons' rights to autonomy and self-determination are fully respected, for all purposes and in all settings.
- (6) In relation to both topics, such legislation should have regard to families and others having a legitimate interest in relevant matters concerning an individual, and to those with relevant statutory roles and functions.
- (7) The legislation should be drawn so as to comply with mandatory human rights norms, and to respect other relevant human rights norms.
- (8) The formulation of legislation should be preceded by further investigation and by consultation, following upon these recommendations. Matters for further investigation, and for consultation, should include the following:
- What are current practices, and views as to good practice, among relevant professionals?
  - What is the experience of people with lived experience; of their families and carers; and of the supporting roles of lawyers, advocates, interested organisations, and other stakeholders?
  - What actions are members of the public encouraged to take, and by whom, and how well are those recommended actions supported by existing law?
  - What existing initiatives have been taken (locally or nationally) to encourage and assist people in advance care planning, and what documents and methods (formal or informal) are in use?
  - What should be an appropriate and integrated evaluation of all of the foregoing?
  - What conclusions should be drawn from that evaluation?
  - What should be appropriate proposals and recommendations for the content of suitable legislation?
  - What would be the terms of suggested legislation?
- (9) Once legislation has been passed, there should be a programme of public awareness-raising and information, provision of professional and other training, and preparation of any necessary secondary legislation, Codes of Practice, Guidance, and the like. As occurred following upon passing of the 2000 Act, all of the foregoing should be coordinated by an implementation steering group.

## 8. Advance choices

The following recommendations relate to the suggested main characteristics of a legislative scheme for advance choices. Although we recognise that full consultation with interested parties would be required in accordance with recommendation (7) above, we consider that the issues set out below could form the basis of a preliminary discussion around the matters which would require to be addressed, recognising that this is a developing area of practice and human rights compliance, and for many a novel area of law.

## 8.1 Scope

(10) There should be no limitation on possible scope of advance choices, except (in the case of advance instructions) in accordance with the test of legality set out below. We do not recommend specific public policy exemptions.

(11) The granter should be able to do and decide by way of an advance instruction anything that the granter could do or decide with immediate effect if fully capable. However, the test of legality should apply at the point or points in time at which the advance instruction becomes operable, rather than at time of granting.

## 8.2 Age at which a person can grant an advance choice

(12) The Age of Legal Capacity (Scotland) Act 1991 should apply to advance instructions. A person over the age of 16 could issue an advance instruction. A person under 16 could issue an advance instruction about medical matters only, where they have sufficient maturity and understanding in terms of section 2(4) of the 1991 Act. If the law were to change, then this would require to be reconsidered. There should be no age limit for issuing advance statements, other than for mental health advance statements under existing legislation, and any continuation of a minimum age limit in any replacement legislation.

## 8.3 Formality

(13) There should be maximum accessibility to the possibility of creating an advance choice, subject to minimum requirements for certainty and effectiveness.

(14) We recommend that the minimum requirement for validity of an advance choice is that it should be made or recorded in writing or in any other enduring and permanent form (including voice records and video, or other technologies that might become available), provided that the identity and authorship of the granter can at any relevant future point readily be ascertained with certainty.

(15) For any of the contents of an advance choice to have the status of an advance instruction rather than an advance statement, that intention should be clearly indicated.

(16) It should not be competent for any advance choice to authorise withholding or withdrawing life-preserving treatment unless the advance choice specifically and unequivocally states that intention.

(17) Those should be the minimum requirements for validity. The requirements for “top-level” advance choices should accord maximum effectiveness. For documents with some of the requirements for top-level status, but not all of them, the degree of compliance with top-level requirements should be relevant to considerations as to whether the advance choice should be disapplied in particular circumstances (see recommendations on disapplication below).

(18) The requirements for top-level status should be as follows:

(a) The minimum requirements for validity stated above should be met.

(b) The advance choice should be accompanied by a certificate that at time of granting the granter had adequate capacity. The certifier should certify from the certifier’s own knowledge, including relevant

professional skills. “Second-hand certification”, as is possible for certification of powers of attorney under the 2000 Act, should not be permitted. There should be a separate certificate, again by a person able to grant it from his or her own knowledge, that the granter was not acting under undue influence and that there were no other vitiating factors. In relation to both certificates, each certifier should state any qualifications relevant to being able to grant the certificate. Where the same person can properly grant both certificates, the same person may do so.

(c) At least one of the certifiers should certify that the advance choice was issued in the certifier’s presence. There should be no further requirement for witnessing.

(d) The advance choice should be centrally registered under a system in which basic facts of the advance choice should be accessible immediately in an emergency, and as quickly as they may reasonably be required in any other situation. The basic facts should include whether the individual has issued an advance choice, whether it is a top-level advance choice, whether it is still in force, and whether it includes advance instructions and/or advance wishes in relation to (i) any property and financial matters, and/or (ii) medical or other healthcare matters, and/or (iii) other personal welfare matters. On cause shown, the full advance choice, in the form in which it has been created, should be made accessible to an applicant within such timescale as might reasonably be required, subject to a discretion on the part of the registrar to withhold such disclosure in whole or in part for reasons stated by the registrar, which withholding may be overruled, partly overruled, or confirmed by a court upon application by a person having an interest.

(19) Any advance choice which does not meet the minimum requirement for validity could still be considered as a past or present expression of wishes and feelings, or of will and preferences, for the purposes of section 1(4)(a) of the 2000 Act or any successor provision. A valid advance choice should have enhanced status.

#### **8.4 Revocation versus disapplication**

(20) Revocation is, by definition, irreversible. Revocation of an advance choice should be explicit and made to the same level of formality as the advance choice, by an adult acting competently and in the absence of undue influence, fundamental error, or other vitiating factor.

(21) There may arise circumstances where an adult may, verbally or by conduct when confronted with particular circumstances, say or indicate that they do not wish their advance choice to be applied. Particularly in circumstances where it might be impractical or impossible for the adult to create a fresh advance choice, or at least one to the same standard of formality as the original advance choice, to deprive the adult permanently of any benefit from having created the original advance choice might not coincide with the adult’s long-term will and preferences. It is better that such a situation be addressed in terms of “Should the provisions of the advance choice be applied in this particular matter at this point in time?”, rather than “Should an advance choice that reflected the will and preferences of the adult at time of creation be irrevocably terminated?”. There should be a clear emphasis on considering the possibility of disapplication, as opposed to revocation.

(22) Questions of disapplication should not arise in relation to advance wishes. Advance wishes should only ever have persuasive effect. Any review of their status should be a matter for the SMHLR, though if

the effect of section 1(4)(a) of the 2000 Act is to be retained, it is recommended that the SMHLR consider introducing a qualification to the same effect as in the 2005 Act, giving particular force to wishes stated in writing, with the possibility of further enhancement of an advance statement that qualifies as a top-level advance choice.

(23) Issues about disapplication of mental health advance statements should be a matter for the SMHLR.

(24) It should be possible for advance instructions to be disapplied if, but only if, specified criteria were met. We recommend that the approach should be to permit disapplication upon a reasonable judgement that disapplication at a particular time and in particular circumstances would accurately coincide with the granter's will and preferences, or a best interpretation of the granter's will and preferences, having regard to (and appropriately balancing if necessary) the following criteria:

- There should be a strong presumption against disapplying top-level advance instructions in any situation to which they apply.
- There should be a presumption against disapplying any advance instructions, the strength of which presumption should be proportional to the extent to which some of the requirements for top-level status have been applied.
- In medical matters, there should be a presumption against disapplication if the granter has taken medical advice in relation to the terms of relevant provisions of the advance instructions.
- In medical matters, there should be a strong, and normally overriding, presumption in favour of disapplying an advance instruction in relation to any care or treatment which, in absence of the advance instruction, would normally be offered and given, and which the granter indicates that the granter wishes to be given.

(25) Further factors which should be taken into account in making a decision regarding disapplication should include:

- The length of time that had elapsed since the advance choice was made, or last reviewed.
- That there were reasonable grounds for believing that circumstances existed which the individual did not anticipate at the time of the advance choice and which would have affected the individual's choice had the individual anticipated them.
- That in the case of medical matters, such changes in circumstances might include advances in treatment, developments of new treatments, or significant mitigation of potential disadvantages of existing treatments.

(26) In assessing applicability/disapplication, and related matters of interpretation, there should be a presumption that individuals should have the maximum range of choice.

(27) We would envisage that - except in certain emergency situations - decisions to disapply an advance choice will amount to interventions in terms of section 1 of the 2000 Act (or any similar succession principles), and will require to be made in accordance with the principles of the Act, CRPD (so far as applicable), and the criteria set out above.

(28) Disapplication should have no effect on the validity of the instrument containing the advance choice. However, consideration should be given to statutory provisions, equivalent to the relevant provisions of the 2005 Act, to disapply damages where certain criteria were met.

(29) In the event of valid revocation, the same requirements for registration of the revocation would apply as for registration of the advance choice, though for practical reasons the registrar might find it necessary to state requirements.

### **8.5 Application to the court**

(30) The possibility of an application to the court should not be ruled out at this stage, and there should also be a mechanism for an application for rectification. There should be provision for an application to the body maintaining the register in the first instance, followed by application to the court.

(31) There may be scope for an independent oversight body with a similar role to that of the Mental Welfare Commission.

(32) It would be a matter of policy whether to introduce a mandatory requirement for approval of decisions to disapply. We recommend that any such requirement be limited (a) to top-level advance choices and (b) to situations where time permits such a procedure to be followed and (c) to matters where such requirement would be proportionate. Otherwise, the onus would be upon an aggrieved party to bring a challenge.

### **8.6 Effect of subsequent intervention or guardianship order**

(33) As a general principle, a voluntary<sup>46</sup> measure should never be “trumped” by an involuntary one.

(34) The only exception should be where, upon rigorous application of the 2000 Act principles or any similar successor applicable principles, it is shown that to override an existing voluntary measure, and thus to override the clear will and preferences of the adult at time of granting, is necessary.

### **8.7 Trigger for operation of advance choice**

(35) An advance choice should apply after loss of capacity, as opposed to operating on an entirely self-directed basis. We recognise the difficulties inherent in this approach as it related to CRPD, but also that such an approach is required until and unless there are changes to Scots law relating to capacity.

(36) “Advance choices”, by definition, are intended to take effect at a point when the person themselves is unable to take the contemporaneous steps required to exercise their legal capacity. We recommend that any statutory provision for advance choices within Scots law proceeds on the basis that, whilst the person should be able to indicate (if they wish) the circumstances under which they may be unable to take those steps, determination of that inability is ultimately a matter for whoever it is who would otherwise be acting upon the person’s contemporaneous decision or action.

<sup>46</sup> As to “voluntary measure”, see Annex A paragraphs 2.7 et seq.

## 8.8 Cross-border application

(37) Effective cross-border application will be a necessary feature of any legislative scheme. The standard approach under private international law should apply, including where applicable the provisions of Hague Convention 35 on the International Protection of Adults (“Hague 35”) or any generally accepted interpretation thereof, though full advantage should be taken of changes and improvements between the date of this paper and preparation of any Scottish legislation to provide for advance choices.

(38) Currently, work is proceeding on preparation by Hague Conference of a practical handbook on the operation of Hague 35, the combined effect of Articles 3 and 4 of which mean that all measures not explicitly excluded from the ambit of the Convention are included, and advance choices (by whatever name) are not explicitly excluded; yet the Convention contains no operational provisions that are drawn so as to be applicable to advance choices<sup>47</sup>. The current approach of the Permanent Bureau of the Hague Conference is to fill this lacuna by adopting a teleological approach under which such provisions of the Convention as could in practical terms usefully be applied to advance choices should be so applied. That approach may or may not be endorsed by a Special Commission meeting of Hague Conference expected to occur later in 2022. We recommend that Scottish Government closely follow any such developments, and should in principle take advantage of any opportunities to opt in to such provisions.

(39) The practical problems caused by the deficiencies and uncertainties in the drafting of Hague 35 have received attention in particular from the European Parliament and the European Commission. The Commission has before it proposals, principally from European Law Institute, for a regulation supplementary to Hague 35 providing clarity and certainty in cross-border situations for measures such as advance choices (by whatever name), and also for powers of attorney, to which some uncertainties also apply. While these would be embodied in a European Union regulation, because of the fully international dimension of these issues the proposals include that non-EU states should be able to opt in to at least some of the relevant provisions. We recommend that Scottish Government closely follow any such developments, and should in principle take advantage of any opportunities to opt in to such provisions.

## 9. Medical decision-making

(40) The aim of the above recommendations is to support greater use of advance choices, enabling those who wish to do so to make decisions about their medical treatment in advance. A move towards greater use of advance choices could lead to a reduction in situations where medical practitioners are required to make ‘difficult choices’ about medical treatment, including withdrawal of treatment.

We recognise, however, that advance choices cannot provide for all situations, that there will be cases where advance choices are disapplied in accordance with the criteria set out above, and that not everyone will wish to or be able to make an advance choice.

<sup>47</sup> All of the operational provisions apply either to measures (such as a guardianship order) taken by a court or administrative authority, or else a “power of representation” under which someone is empowered by the adult to act as the adult’s representative. Neither of these covers an advance choice except in rare circumstances such as when a court has become involved and has made an order, relating to and endorsing the advance choice.

In these situations, we recommend that a statutory formulation of the doctrine of *negotiorum gestio* should apply, supported by clear practical guidance for medical practitioners on their professional and ethical obligations. Developing the content for such guidance is beyond the scope of the present paper, but it is thought that a statutory statement of *negotiorum gestio*, analogous to that found in §677 BGB (of which, see Annex C, p.16-21), could be usefully incorporated into any relevant legislation. Any such statutory formulation should be non-exclusive, and should include any other formulations or applications of the principle in existing Scots law.

§677 BGB presently provides that ‘a person who conducts a transaction for another person without being instructed by him or otherwise entitled towards him must conduct the business in such a way as the interests of the principal require in view of the real or presumed will of the principal’. It is noteworthy that in Scots law at present, the word ‘transaction’ is given an extended meaning to cover medical treatment in statutes concerning adults and children alike<sup>48</sup>. It is consequently thought that (with the inclusion of a sufficiently clear interpretation section in any relevant legislation), the statutory statement of *negotiorum gestio* in German law could be readily adapted to fit within Scots law.

48 See Age of Legal Capacity (Scotland) Act 1991, section 9(d) and *M's Guardian v Greater Glasgow Health Board* [2021] 11 WLUK 346

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