

# 從里斯本宣言探討病人權利

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# 健康權(right to health)與人權觀念的演變

## ——里斯本宣言的環境背景

- 1946 WHO章程
- 1966 WHO經濟、社會、文化權利國際公約
- 1994 WHO歐洲事務會議，通過《歐洲促進患者權利宣言》
- 2000 《經濟、社會、文化權利》委員會一般性意見：

第14條，締約國就健康權負有尊重、保護、和實現等三個義務

第42條，雖然是國家締約，但包括專業人士在內的社會所有成員（個人與組織）都負有實現健康權的責任，締約國家應該提供履行相關責任的環境。

# 世界醫師協會呼應健康權的歷史脈絡

## ——里斯本宣言的定位

- 1948年9月 通過《世界醫師協會日內瓦宣言(World Medical Association Declaration of Geneva)》
- 1949年10月 通過《關於醫師倫理的國際綱領(WMA International Code of Medical Ethics)》
- 1968年8月 修訂《關於醫師倫理的國際綱領(WMA International Code of Medical Ethics)》
- 1983年10月 修訂《關於醫師倫理的國際綱領(WMA International Code of Medical Ethics)》
- 1981年 通過《關於患者權益的里斯本宣言(WMA Declaration of Lisbon on The Rights of The Patient)》
- 1995年9月 修訂《關於患者權益的里斯本宣言(WMA Declaration of Lisbon on The Rights of The Patient)》

# 里斯本宣言的背景說明與基本立場

## —— PREAMBLE (前言)

- The relationship between physicians, their patients and broader society has undergone significant changes in recent times. (醫師、病人、與社會關係之間的遽變)
- While a physician should always act according to his/her conscience, and always in the best interests of the patient, equal effort must be made to guarantee patient autonomy and justice. (根據良知與病人最大利益行動之時，也要對保障病人的自主與正義有著相同的付出)
- The following Declaration represents some of the principal rights of the patient which the medical profession endorses and promotes. Physicians and other persons or bodies involved in the provision of health care have a joint responsibility to recognize and uphold these rights. (醫療專業人員需要為以下病人的權利負共同的責任與保證。)
- Whenever legislation, government action or any other administration or institution denies patients these rights, physicians should pursue appropriate means to assure or to restore them. (如果透過立法與政府的力量否決了病人這些權利，醫師應當採取適當的方法來確保或是恢復這些權利)
- In the context of biomedical research involving human subjects - including non therapeutic biomedical research - the subject is entitled to the same rights and consideration as any patient in a normal therapeutic situation. (在生物醫學研究的脈絡中的受試者也享有相同的權利，一如在正常治療的情境)

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# 里斯本宣言規範的病人權利事項

- **Right to medical care of good quality**
  - **Right to freedom of choice**
  - **Right to self-determination**
  - **The unconscious patient**
  - **The legally incompetent patient**
  - **Procedures against the patient's will**
  - **Right to information**
  - **Right to confidentiality**
  - **Right to Health Education**
  - **Right to dignity**
  - **Right to religious assistance**
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# Right to medical care of good quality

- Every person is entitled without discrimination to appropriate medical care. (接受醫療不能有歧視)
- Every patient has the right to be cared for by a physician whom he/she knows to be free to make clinical and ethical judgements without any outside interference. (專業人員的判斷不能受臨床或是倫理之外的干擾因素影響)
- The patient shall always be treated in accordance with his/her best interests. The treatment applied shall be in accordance with generally approved medical principles. (依照被認可的醫療原則與病人的最佳利益給予治療)
- Quality assurance always should be a part of health care. Physicians, in particular, should accept responsibility for being guardians of the quality of medical services. (醫師必須負起醫療照護品管的責任)
- In circumstances where a choice must be made between potential patients for a particular treatment which is in limited supply, all such patients are entitled to a fair selection procedure for that treatment. That choice must be based on medical criteria and made without discrimination. (分配稀有醫療資源時必須根據醫療的準則與沒有歧視的原則來進行治療步驟的選擇)
- The patient has the right of continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care. (醫師必須互相協調、作萬全的相關安排，以確保醫療照護的延續性)

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# Right to freedom of choice

- The patient has the right to choose freely and change his/her physician and hospital or health service institution, regardless of whether they are based in the private or public sector. (自由選擇醫師與醫療機構的權利)
  - The patient has the right to ask for the opinion of another physician at any stage. (隨時都有徵詢其他意見的權利)
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# Right to self-determination

- The patient has the right to self-determination, to make free decisions regarding himself/herself. The physician will inform the patient of the consequences of his/her decisions. (自主決定權)
  - A mentally competent adult patient has the right to give or withhold consent to any diagnostic procedure or therapy. The patient has the right to the information necessary to make his/her decisions. The patient should understand clearly what is the purpose of any test or treatment, what the results would imply, and what would be the implications of withholding consent. (有知道攸關自主決定相關訊息的權利)
  - The patient has the right to refuse to participate in research or the teaching of medicine. (有權利拒絕參與研究或是教學)
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# The unconscious patient

- If the patient is unconscious or otherwise unable to express his/her will, informed consent must be obtained whenever possible, from a legally entitled representative where legally relevant. (失去意識的病人必須尋求法定的代理人同意)
- If a legally entitled representative is not available, but a medical intervention is urgently needed, consent of the patient may be presumed, unless it is obvious and beyond any doubt on the basis of the patient's previous firm expression or conviction that he/she would refuse consent to the intervention in that situation. (除非病人曾有明確的表達，否則在危急的狀態法定代理人不可得時，可將病人的同意視為當然)
- However, physicians should always try to save the life of a patient unconscious due to a suicide attempt. (即使是自殺式去意識的病人，醫師應該盡量嘗試挽救其生命)

# The legally incompetent patient

- If a patient is a minor or otherwise legally incompetent the consent of a legally entitled representative, where legally relevant, is required. Nevertheless the patient must be involved in the decision making to the fullest extent allowed by his/her capacity. (即使是法定失能的病人也要讓她／他在過程中盡量參與決策)
- If the legally incompetent patient can make rational decisions, his/her decisions must be respected, and he/she has the right to forbid the disclosure of information to his/her legally entitled representative. (當法定失能的病人做出合理的決定時必須與以尊重，並享有拒絕讓法定代裡人知悉相關訊息的權利)
- If the patient's legally entitled representative, or a person authorized by the patient, forbids treatment which is, in the opinion of the physician, in the patient's best interest, the physician should challenge this decision in the relevant legal or other institution. In case of emergency, the physician will act in the patient's best interest. (如果病人的代理人做出違反病人最佳利益的決定時，醫師有義務在相關的法律機構挑戰這項決定，如在危急時則以病人的最佳利益從事醫療行為)

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# Procedures against the patient's will

- Diagnostic procedures or treatment against the patient's will can be carried out only in exceptional cases, if specifically permitted by law and conforming to the principles of medical ethics  
( 僅有在法律授權或是符合醫療倫理時，可以採取違反病人意願的診斷或是治療步驟 )
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# Right to information

- The patient has the right to receive information about himself/herself recorded in any of his/her medical records, and to be fully informed about his/her health status including the medical facts about his/her condition. However, confidential information in the patient's records about a third party should not be given to the patient without the consent of that third party. (病人有權知道病例上攸關她／他的訊息與醫療健康狀況，但病例上如有攸關第三者的保密資訊，則應徵得第三者的同意才能透露給病人)
- Exceptionally, information may be withheld from the patient when there is good reason to believe that this information would create a serious hazard to his/her life or health. (只有在訊息揭露可能對病人造成重大生命或是健康危害時，才是可隱蔽資訊的例外狀況)
- Information must be given in a way appropriate to the local culture and in such a way that the patient can understand. (必需以符合地方文化的方式來合適地給予資訊，確保病人能夠理解)
- The patient has the right not to be informed on his/her explicit request, unless required for the protection of another person's life. (病人有明確表達不要被告知的權利，除非是基於保護其他人的生命)
- The patient has the right to choose who, if anyone, should be informed on his/her behalf. (決定何人可被告知的權利)

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# Right to confidentiality

- All identifiable information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind, must be kept confidential, even after death. Exceptionally, descendants may have a right of access to information that would inform them of their health risks. (即便在病人死後都應落實保密原則，除非後代子孫需要獲得攸關他們健康風險的資訊)
  - Confidential information can only be disclosed if the patient gives explicit consent or if expressly provided for in the law. Information can be disclosed to other health care providers only on a strictly "need to know" basis unless the patient has given explicit consent. (除非是法律明確的規範或是病人明確的意願表達，保密訊息才得以揭露，提供給其他的健康服務人員是在專業必須的基礎上，否則仍應徵得病人明確的同意)
  - All identifiable patient data must be protected. The protection of the data must be appropriate to the manner of its storage. Human substances from which identifiable data can be derived must be likewise protected. (所有可辨認出病人的資料都必須被保護，資料儲存的方式必須符合保密原則，可衍生出辨人病人資訊的人體物質都必須被保護)
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# Right to Health Education

- Every person has the right to health education that will assist him/her in making informed choices about personal health and about the available health services. The education should include information about healthy lifestyles and about methods of prevention and early detection of illnesses. The personal responsibility of everybody for his/her own health should be stressed. Physicians have an obligation to participate actively in educational efforts. (每人都有獲得健康教育的權利，內容包括健康的生活模式、疾病預防與早期發現的方法，其中必須強調個人對於自身健康的責任，醫師有義務積極參與相關的教育活動)
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# Right to dignity

- The patient's dignity and right to privacy shall be respected at all times in medical care and teaching, as shall his/her culture and values. (必須根據病人的文化與價值來保障其尊嚴與隱私權)
  - The patient is entitled to relief of his/her suffering according to the current state of knowledge. (有權利根據現存的知識來減輕其痛苦)
  - The patient is entitled to humane terminal care and to be provided with all available assistance in making dying as dignified and comfortable as possible. (人道與舒適的安寧療護)
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# Right to religious assistance

- The patient has the right to receive or to decline spiritual and moral comfort including the help of a minister of his/her chosen religion.
  - 病人有權力接受或是拒絕心靈或是道德上的安慰，包括她／他所選擇宗教之牧師（神職人員）所提供的幫助。
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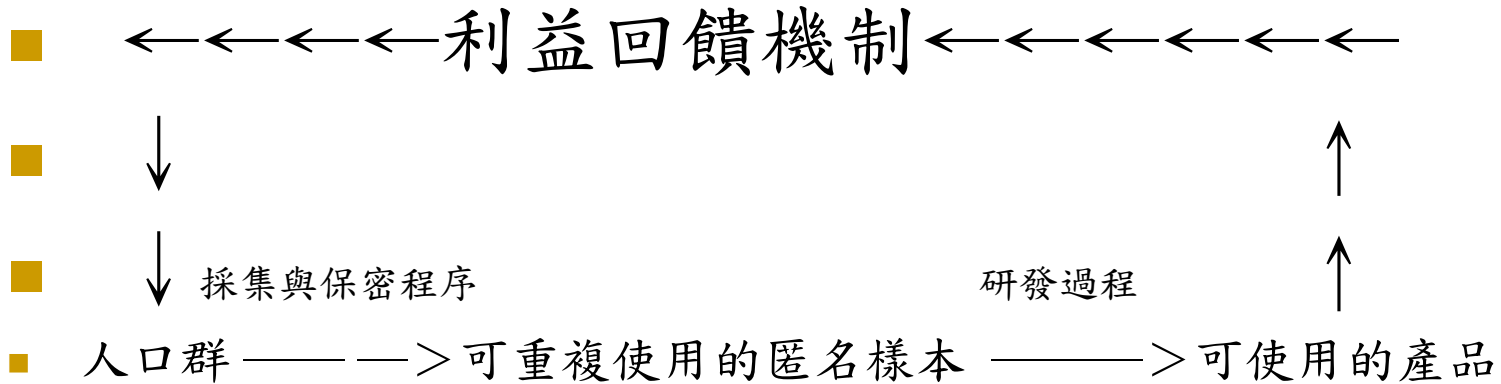
# 總結

- 醫者的角色
  - 教育的努力
  - 文化與價值的敏感度
  - 政治的擔當
  - 引導社會發展的責任
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# 展望

——以生物資訊銀行的建置為例

## ■ Biobank的架構：



# 台灣族群基因資料庫 (Taiwan Biobank)

- 在基因科技躍升的年代，建構台灣族群基因資料庫（Taiwan Biobank）是大規模國人基因資訊收集分析的重要資料系統平台，也是攸關國人健康權益與國家生技發展最重要的基礎建設，成功的要件更是以全體國人的信賴為基礎。要贏的這樣的信賴，必需完整地告知國人基因資料庫運作的機制，協助國人與研究者在不同的層次參與監督相關機制的運作，共同建立符合生命倫理原則的運作模式，由確保公平正義來贏得國人的信賴。
- 台灣族群基因資料庫的建立，攸關個人隱私的保障、群體同意（group consent）機制的建立、務實的應用取向、將為台灣生技產業的發展奠立雄厚的基礎，這一切是以科學為基礎的民主參與和信賴建立的過程。首先，由於掌握基因序列代表著掌握個人與族群最私密的資訊，所以台灣基因資料庫的組成需要非常嚴密的多重保密措施，並建立相關的安全認證系統，嚴格落實保密原則以便積極保障個人隱私。



# 呼應里斯本宣言的作為

- 甚 我的相。的況商方  
群 訂規範等運。的  
族 業訂規例機同的或  
殊 商是律條的體作果應  
特 的同法產贏群合政府  
關 該法產贏群合政府  
攸 相 應 相 結 展 雙 人 商 政  
立 蘊 件 落 實 連 結 展 雙 人 商 政  
建 也 事 在 作 產 在 與 料 果  
的 危 大 的 應 合 技 是 構 資 後  
庫 安 重 也 廠 與 就 機 因 的  
資 的 生 法 的 廠 與 就 機 因 的  
因 續 民 護 內 健 康 為 研 究 基 重  
基 存 計 保 國 人 的 作 數 族 常 嚴  
群 種 國 全 與 國 理 過 我 國 非 任  
族 人 關 安 先 造 倫 透 過 我 國 非 任  
灣 民 攸 因 優 先 造 倫 透 過 我 國 非 任  
台 國 此 基 因 創 命 就 攸 將 全 的  
最 全 體 如 群 下 規 合 下 就 將 全 的  
後 至 益 國 族 提 法 不 況 下 就 將 全 的  
最 至 益 國 族 提 法 不 況 下 就 將 全 的
- 如 果 政 府 無 法 在 這 方 面 贏 得 信 賴 ， 醫 療 專 業 人 員 、 機  
構 、 與 社 群 必 須 根 據 里 斯 本 宣 言 來 督 促 政 府 改 善 。