

出國報告（出國類別：實習）

參與 108 年歐盟執委會
「國家專家專業訓練計畫」
出國報告

服務機關：衛生福利部國民健康署

姓名職稱：柯昀瑤技士

派赴國家/地區：比利時/布魯塞爾

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報告日期：109 年 3 月 18 日

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摘要

國家專家專業訓練計畫(Program for National Experts in Professional Training, NEPT)，旨在藉由歐盟會員國、歐洲自由貿易聯盟成員國(挪威、冰島、瑞士、列支敦斯登)及其他第三方政府單位官員派員至歐盟相關總署短期實習，促使參訓官員瞭解歐盟執委會之政策及運作方式，並提供自身專業知識及工作經驗與見習單位交流。鑒於歐盟為歐洲地區規模最大的區域性經濟合作國際組織，其影響力除了歐洲地區，於全球社會、經濟及環境面向，都有不容小覷的國際影響力，故透過參加本次專業訓練計畫，除了可以了解歐盟執委會之政策制定、工作模式及會員國間溝通協調等運作方式外，亦可強化臺歐關係，促進未來長期交流。

職於歐盟執委會衛生及食品安全總署(Directorate-General for Health and Food Safety, DG SANTE)第二司(Unit B- Health Systems, Medical Products and Innovation)第3處(Unit B3- European Reference Networks and Digital Health)受訓學習，並任職於該處的歐洲參考網絡團隊，該團隊之主責業務歐盟參考網絡自 2017 年成立至今，已由部署、執行階段，逐步邁向監控及初步結果評估階段，其業務包括召開參考網絡協調員(Coordinator)會議及成員國委員會(Board of Member States)會議、5 個工作小組(分別為：研究、監測、知識建構、法律及利益關係者、整合體系)運作及開會召開、資通訊(Information Technology, IT)平台規劃、網絡新成員申請審查及其他行政事項(如預算編列)等。本次實習主要工作為規劃歐洲參考網絡教育訓練的總體策略、協助電子報文章整理及編輯以及參與各項會議，藉由此實習機會，實質參與該部門政策制定、執行、及與各成員國、利害關係團體協商等實務工作。

本計劃為了解歐盟的政治、文化、實際社會情況及歐盟衛生及食品總署的具體工作提供了理想的機會，由於東西方思維及不同國家思考方式的差異，不論是實習方或者實習單位皆可以從雙方那裡獲得豐富的反饋，達到雙贏。此外，本計畫能帶動歐盟及台灣之間更多的互動，促進未來臺歐健康議題之合作。

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壹、目的

國家專家專業訓練計畫(Program for National Experts in Professional Training, NEPT)，旨在藉由歐盟會員國、歐洲自由貿易聯盟成員國(挪威、冰島、瑞士、列支敦斯登)及其他第三方政府單位官員派員至歐盟相關總署短期實習，促使參訓官員瞭解歐盟執委會之政策及運作方式，並提供自身專業知識及工作經驗與見習單位交流，達到雙方互惠互利之雙贏交流模式。鑒於歐盟為歐洲地區規模最大的區域性經濟合作國際組織，其影響力除了歐洲地區，於全球社會、經濟及環境面向，都有不容小覷的國際影響力，故透過參加本次專業訓練計畫，除了可以了解歐盟執委會之政策制定、工作模式及會員國間溝通協調等運作方式外，亦可強化臺歐關係，促進未來長期交流合作。

貳、過程

實習期間獲安排於歐盟執委會衛生及食品安全總署(DG SANTE)第二司(Unit B-health systems, medical products and innovation)第3處(Unit B3- European Reference Networks and Digital Health)受訓學習，隨歐盟政策官(指導員)參與歐洲參考網絡相關會議、處務會議、歐洲參考網絡小組會議、數位健康相關會議等，從中參與該部門歐洲參考網絡及數位健康政策制定、執行、及與各成員國、利害關係團體協商等實務工作，以下就歐盟組織架構與業務職掌、歐盟數位健康政策方向及本次國家專家專業訓練實際內容等詳述如下：

一、 歐盟(European Union)

(一) 歐盟簡介

歐盟（EU）為歐洲最大的政治經濟主體，是一個擁有政策決策權的跨國組織，其立法不僅影響成員國本身，而且間接影響世界其他地區。歐盟涵蓋 27 個成員國，以 24 種官方語言運作，涵蓋人口約 4.47 億，GDP 約 20 兆美元，佔世界總 GDP 的 24%，其各機構分佈於歐洲多個城市，但主要以布魯塞爾為機構分佈的中心。

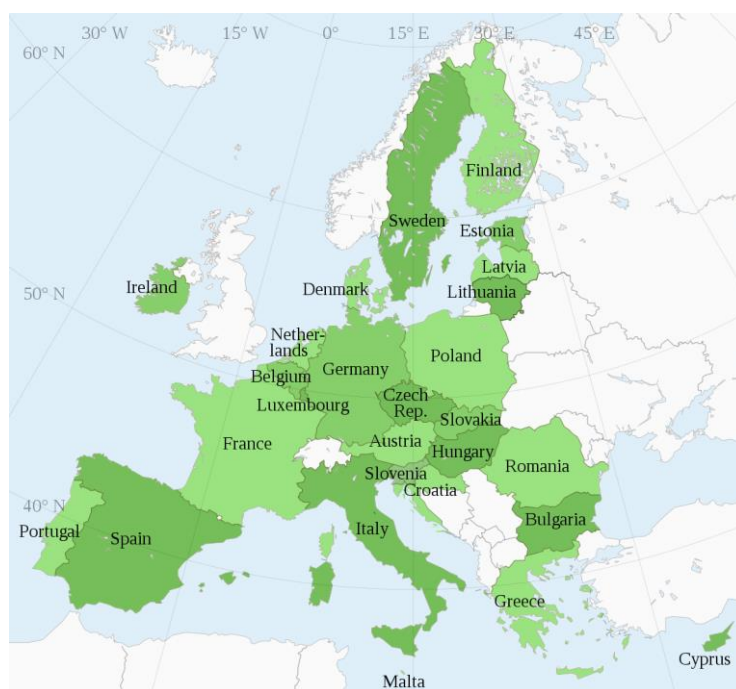


圖 1 2020 年歐盟成員國地圖¹

(二) 歐盟運作架構

歐盟整體的政治方向及優先事項由歐盟 27 個成員國的總理、首相或總統組成的**歐盟理事會(EU Council)**共同決定。其決策過程涉最主要三個核心機構：行政執行機構－**歐盟執委會(European Commission)**及二大立法機構－**歐盟議會(European Parliament)**及部長理事會(Council of the EU)。分別詳述如下：

¹ https://en.wikipedia.org/wiki/Member_state_of_the_European_Union

1. **歐盟執委會(European Commission)**：為歐盟最高的行政執行機構，每 5 年為一任期，下設總署(如衛生及食品安全總署等)和附屬機構，主要有 4 大任務：(1)確保條約和歐盟法律的執行；(2)提出法案草案；(3)協調、執行及管理政策及預算；(4)在國際舞台上代表歐盟。
2. **歐盟議會(European Parliament)**：為歐盟唯一由直接投票選舉產生的機構，自 1979 年起，每 5 年舉行一次，主要有 3 大權力：(1)立法權，與理事會共同制定歐盟新法；(2)預算監督權，與理事會共同組成歐盟預算機構，並共同商定年度預算，所有預算案皆須議會主席簽署，並監督年度預算的執行情況；(3)監督歐盟執委會的工作項目，並有權批准或拒絕接受歐盟委員會主席和委員人選。
3. **部長理事會(Council of the EU)**：匯集 27 個歐盟會員國部長級成員，為歐盟決策的核心，也是歐盟的立法機構(與歐盟議會共同運作)。

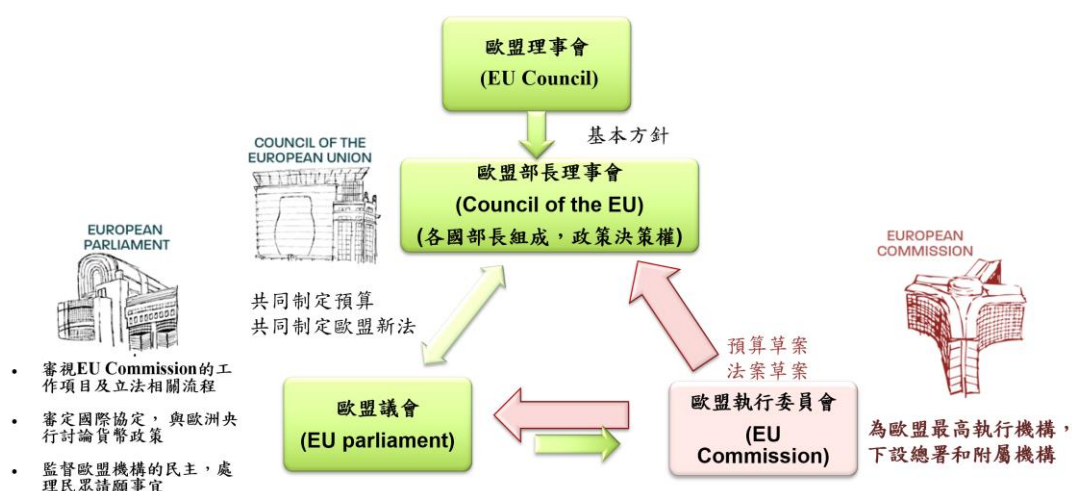


圖 2 歐盟運作架構

(三) 執行委員(The Commissioners)：2019-2024

執行委員五年為一任期，由來自 27 個歐盟成員國的代表組成(需由歐盟議會及

部長理事會共同同意才可擔任)，27 名代表於任期內將一起領導各政策的執行。108 年年末適逢新舊執行委員交接，新任歐盟委員會主席德國烏爾蘇拉·馮德萊恩（Ursula von der Leyen）於 108 年 7 月 16 日當選，並於 108 年 11 月 1 日上就任歐盟委員會主席，新一任期(2019-2024)之執行委員，也於 108 年 11 月 27 日歐洲議會上全數通過，在投票前，當選總統向歐洲議會介紹了她的執行委員成員，並重申各項承諾以因應這一世代的挑戰：包括氣候變遷、數位科技應用及建立社會市場經濟，她呼籲歐洲在世界上發揮應有的領導力，並強調針對需求，歐盟需找到共同解決方案來解決各項挑戰。政策主要六大方向如下²：

1. **歐洲綠色新政(European Green Deal)**：至 2050 年以前達到淨零排放(碳中和)，成為世界上第一個氣候中和大陸（climate-neutral continent）。
2. **為人民服務的經濟(An economy that works for people)**：建立公平的經濟及貨幣聯盟，促進投資並創造就業機會。
3. **適合數位時代的歐洲(A Europe fit for the digital age)**：透過人工智能 (AI) 和數位戰略，為人民和企業服務，同時協助達成 2050 年氣候中和的目標。
4. **促進我們的歐洲生活方式(Promoting our European way of life)**：以平等，寬容和社會公平為願景，建立一個全面的歐洲法治機制。
5. **世界上更強大的歐洲(A stronger Europe in the world)**：從政治，經濟和安全方面著眼於穩定和全區域合作，開放及公平的貿易政策，使歐洲成為具吸引力的商業場所。
6. **歐洲民主的新動力(A new push for European democracy)**：確保參與國際談判的各個階段以及整個立法過程的透明性和完整性，以鞏固與歐洲議會的伙伴關係。

執行委員團隊成員中，衛生健康領域，由賽普勒斯的凱瑞亞基德斯(Stella

² https://ec.europa.eu/info/priorities_en

Kyriakides)主掌，其未來 5 年重點政策如下³：

1. 供應可負擔的藥品(Supply of affordable medicines)。
2. 實行新的醫療器材法規架構(Effective implementation of the new regulatory framework on medical devices)。
3. 使用數位健康來提供高品質的健康照護及降低不平等(Use e-health to provide high-quality healthcare and reduce inequalities)。
4. 創造歐洲健康資料庫以促進資訊交換及研究(Create a European Health Data Space to promote exchanges and research)。
5. 執行歐洲健康行動計畫以對抗多重抗藥性(Implementation of the European One Health Action Plan against Antimicrobial Resistance)。
6. 著重於疫苗接種的宣導 (Prioritise communication on vaccination)。
7. 執行歐洲抗癌計畫 (Put forward Europe’s Beating Cancer Plan)。

(四) 衛生及食品安全總署(Directorate-General for Health and Food Safety, DG SANTE)

衛生及食品安全總署負責歐盟在公共衛生和食品安全方面的政策，包括跨境醫療保健、煙草控制及藥品和醫療器材等，其使命(Mission)為保護及促進歐洲的人類、動植物健康和食品安全，共設 7 個司(A 至 G)，第一司(A: Resource management and better regulation)主責法律、資訊、預算等一般事務，第二、三司(B、C)主責公共衛生，第四至七司(D 至 G)主責食品安全、動植物產品安全、動植物保護等業務。其中二、三司(B、C)業務分述如下：

1. 第二司(B: Health systems, medical products and innovation)負責衛生體系、

³ https://ec.europa.eu/commission/commissioners/2019-2024/kyriakides_en

醫療產品及創新，設有 6 個處(原只有 5 個處，自 109 年 1 月 1 日組織內部調整，新增 B6-醫療儀器)，本次實習單位為第 3 處(B3: European Reference Networks and Digital Health)負責歐洲參考網絡及數位健康。

- 第三司(C: Public health, country knowledge, crisis management)負責公共衛生、國家知識、危機管理，設有 4 個處，其中第 1 處(C1: Health programme and chronic diseases)負責健康計畫及慢性疾病及第 4 處(C4: Health determinants and international relations)負責健康決定因子及國際關係，與本署業務有相關，亦為未來規劃歐洲抗癌計畫的執行單位之一。

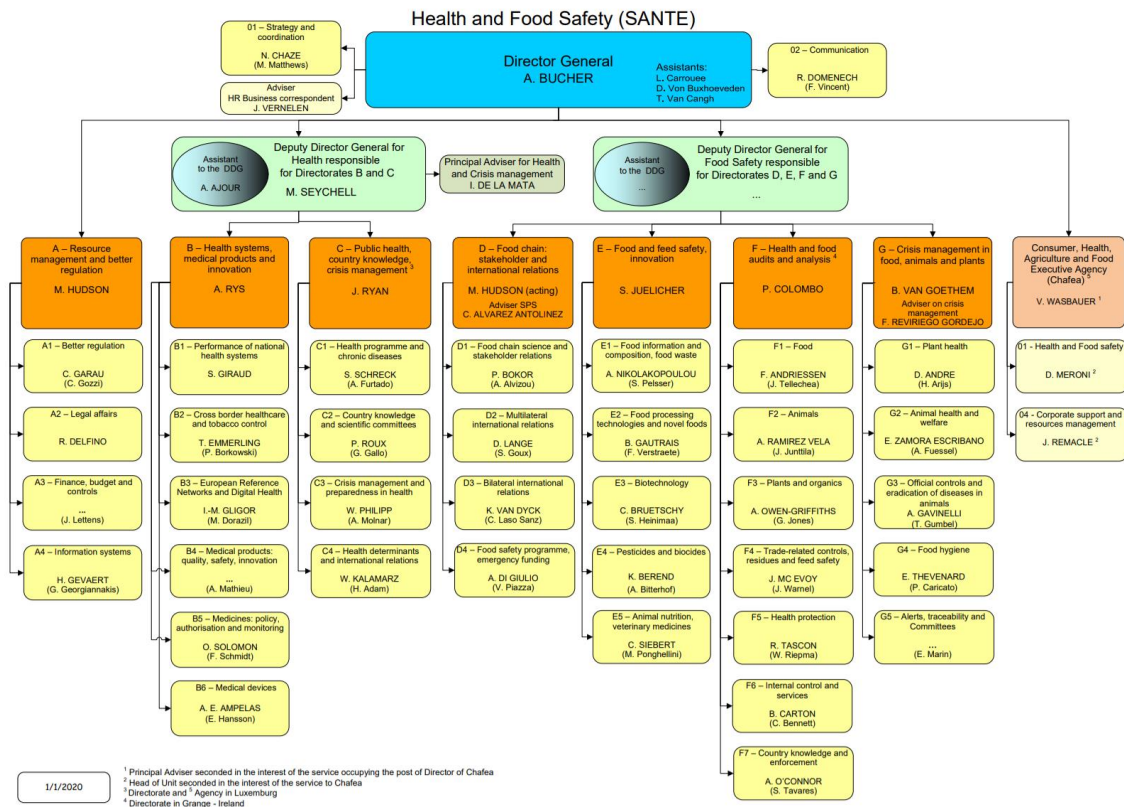


圖 3 衛生及食品安全總署組織架構⁴

⁴ https://ec.europa.eu/info/sites/info/files/organisation_charts/organisation-chart-dg-sante_en.pdf

二、 歐洲參考網絡及數位健康(European Reference Networks and Digital Health)

(一) 歐洲數位健康的現況及未來

歐盟自 2015 年推出「單一數位市場」(Digital Single Market, DSM) 策略，讓人力、服務及資本在數位領域自由流通，在其架構下，發展電子健康數位服務架構(eHealth Digital Service Infrastructure, eHDSI)及歐洲參考網絡(European Reference Networks, ERNs)，促進歐盟成員國間跨境醫療服務，建立罕見疾病專家數位照護資訊平台，提升罕見疾病照護量能，2020 年歐盟執委會發布數位與人工智慧(AI)戰略(Shaping Europe’s Digital Future)提案，試圖為歐洲在數位與 AI 領域訂立產業發展方向，以因應日趨激烈的國際競爭及美國與中國大陸的挑戰，並提案在 2030 年底前，將創造一個醫療數據的單一市場，讓數據可在歐盟內自由流動，重點計畫包括: 歐洲健康資料庫 (European Health Data Space)及 1 百萬基因計畫 (1+ million genomes)等。

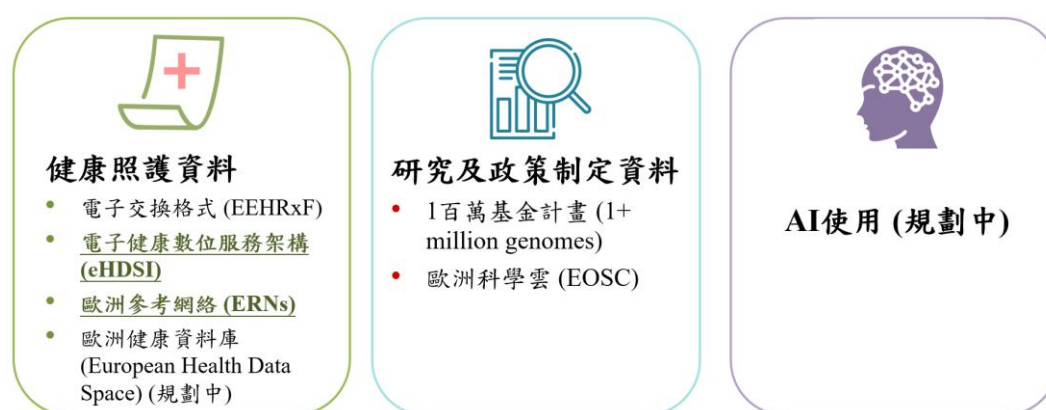


圖 4 歐洲數位健康重點政策

(二) 電子健康數位服務架構 (eHealth Digital Service Infrastructure, eHDSI)

歐盟於 2011 年通過跨境健康照護指令(Directive 2011/24/EU)⁵，並自 2017 年起逐步導入以下兩種電子跨境健康數據交換服務，以確保歐洲公民在歐盟跨國旅遊時皆可獲得持續性醫療照護的權力，並預計至 2022 年將於 22 個歐盟國家中實施：

1. **病情摘述(Patient Summary)**：提供重要的健康狀態簡述及數據，例如過敏、目前用藥、過去病史、手術等，當患者來自另一個歐盟國家並且可能存在語言溝通障礙時，此病情摘述可以為醫生提供必要的資訊。截至 2019 年底，盧森堡、克羅埃西亞、捷克、馬耳他、葡萄牙已經可以提供病情摘述電子交換的服務。
2. **電子處方(ePrescription, eDispensation)**：藉由電子處方由居住國傳遞至旅行國，使歐盟公民可以在另一個歐盟國家/地區的藥局中取得處方藥。截至 2019 年底，芬蘭、愛沙尼亞、克羅埃西亞已經可以提供電子處方電子交換的服務。

本項政策的數據控制權仍屬於每個國家及其機構，由國家層級建立該國的國家聯絡據點(National Contact Point, NCP)，作為該國與其他國家間健康數據傳遞的中介，每個國家皆有各自不同的國家層級網絡，由負責電子健康照護的主管部門協調及參與，並與相關機構及利益關係機構(如負責衛生醫藥數據保護、研究、資訊安全的國家機構)合作，病患將透過其國家的國家聯繫據點，獲得跨境醫療的所有行政程序、權益等相關資訊。

⁵ <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32011L0024&from=EN>

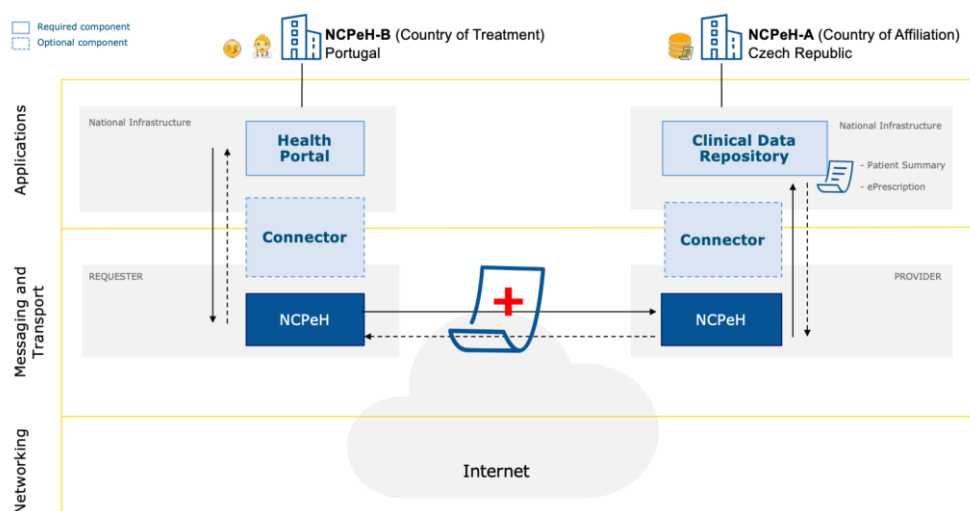


圖 5 電子健康數位服務之國家間互通性傳遞圖

(三) 歐洲參考網絡 (European Reference Networks, ERNs)

歐洲參考網絡是罕見及複雜疾病專家間的自願跨界合作虛擬平台，為根據跨境健康照護指令(Directive 2011/24/EU)而設立的政策之一，並自 2017 年 3 月開始實施。由於在各個國家罕見及複雜疾病的專業知識都較稀少且分散於各國的各機關，因此建立歐盟參考網絡，其概念是讓醫療知識藉由虛擬平台共享，使罕見疾病患者獲得快速，準確診斷的機會，而不是由患者自行出國尋找醫療資源。歐洲參考網絡能打破專家和患者的孤立，減少罕病照護不平等，並促進患者參與的機會，以最大化歐盟的互助合作，來強化歐盟國人民的健康福祉。

該網絡建立了 24 個主題的參考網絡，成員來自 26 個歐盟成員國加上挪威，並包含了 300 多家醫院中的 900 多個專業醫療團隊。各個網絡成員提案主要由歐盟成員國發起，每個網絡由來自 8 個以上不同成員國內的 10 個以上醫療照護機構/中心(Health providers)組成，各個成員國負責以該國的行政程序批准希望成為 ERN 成員的醫療照護提供者，並提交申請至歐盟執委會，審查程

序最終由成員國委員會(Board of Member States)核准所有主題參考網絡的組成。歐盟執委會於 2016 年開放第一波網絡提案申請，並於 2017 年 2 月核准了 24 個參考網絡，每個參考網絡皆由 1 個醫療照護機構/中心擔任協調單位，且由該中心指定一人作為該參考網絡的協調員(Coordinator)，為了增加各個歐盟參考網絡的醫療照護機構/中心於歐盟成員國的覆蓋率，歐盟執委會於 2019 年 11 月開放第二波網絡成員提案申請。此外，歐盟執委會持續為網絡協調員提供資通訊技術支援及資金補助，如歐盟衛生計劃(EU Health Programme)及歐盟研究計畫地平線 2020(Horizon 2020)。

24 個參考網絡為不同主題疾病類別(如自體免疫性疾病、兒童癌症或代謝症候群等)所組成的網絡組織，每個參考網絡的大小(即成員數)及所涵蓋疾病的範圍皆不相同，且診斷及治療取決於疾病的特異性及疾病複雜性，而所需的資源可能在不同的參考網絡及專業中心之間有所不同，患者無法直接連繫歐盟參考網絡，而是由患者的醫療照護提供機構取得患者的同意後，將患者的病歷資訊轉交給其所在國家的參考網絡成員，且需符合其國家衛生體系的作業規範。

24 ERNs 

ERN BOND	Bone Diseases	ERN EuroBloodNet	Onco-Hematological Diseases
ERN CRANIO	Craniofacial anomalies and ENT disorders	ERN EUROGEN	Urogenital Diseases
Endo-ERN	Endocrine Conditions	ERN EURO-NMD	Neuromuscular Diseases
ERN EpiCARE	Rare and Complex Epilepsies	ERN GUARD-HEART	Diseases of the Heart
ERKNet	Kidney Diseases	ERN ITHACA	Congenital Malformations and Intellectual Disability
ERN GENTURIS	Genetic Tumour Risk Syndromes	MetabERN	Hereditary metabolic diseases
ERN-EYE	Eye Diseases	ERN PaedCan	Paediatric Cancer
ERNICA	inherited and congenital anomalies	ERN RARE-LIVER	Hepatological Diseases
ERN-LUNG	Respiratory Diseases	ERN ReCONNET	Connective Tissue and Musculoskeletal Diseases
ERN-RND	Neurological Diseases	ERN RITA	Immunodeficiency, AutoInflammatory and Auto Immune Diseases
ERN-Skin	Skin Disorders	ERN TRANSPLANT-CHILD	Transplantation in Children
ERN EURACAN	Solid Adult Cancers	VASCERN	Multisystemic Vascular Diseases

圖 6 24 個主題之參考網絡⁶

⁶ https://ec.europa.eu/health/ern/networks_en

參考網絡運用網絡資通訊(Information Technology, IT)平台支緩各項遠程通訊及醫療訊息傳遞，此 IT 平台允許每個參考網絡中的醫學專家團隊在線上共享病患病歷並藉由視訊會議討論該患者案例，且該平台亦可處理及收集大量臨床數據，建立罕見及複雜疾病病歷資料庫，以提供未來進一步研究。應用平台包括：(1)罕病臨床病患管理平台(the ERN Clinical Patient Management System, CPMS)：主要的病患資訊管理系統，進行臨床訊息、病患檢驗及診斷數據的交換，如醫學檢驗影像等，並可使用網絡會議及視訊臨床會議，由專家相互討論，以提供精準的病情診斷及治療；(2)罕病溝通協作平台(the ERN Collaborative Platform for Communication and Collaboration)：專家、病患及其家屬合作及交流平台，類似臉書社團，提供疾病資訊交流、文件管理及課程活動召開等，但不傳遞病患的病歷數據；(3)罕病公開網站(europa.eu 網域名及相關個人網站)：提高大眾對罕見疾病的認識，與民眾、病人及醫療照護專業人員共享知識，並發行臨床指南及病人指南等。

(四) 歐洲健康資料庫 (European Health Data Space)

歐洲健康資料庫的建立，主要目的為歐盟成員國間健康數據的共享及鏈接。鑒於醫療數據對於提高歐洲人民醫療照護品質方面有巨大潛力，然而健康數據的收集在歐盟各國仍呈現高度分散，歐盟執委會認為醫療數據轉型的關鍵在於如何以(1)個人可以信任的方式及；(2)研究者及創新者可以使用且安全的形式提供，然而，現階段歐盟各國面臨數據分散化、互通性挑戰、法律制度落差、醫療資訊創新的低普及率及公眾信任的建立(包括確保共享健康數據時的安全性及道德標準)等挑戰。為此，歐盟層級的行動旨在建立一個設計完善的歐洲衛生數據空間，在歐盟及國家層級制定適當的執行框架，並確保該制度的公開、透明及有效性，此政策前提如下：

1. 國家主管單位須依據一般資料保護規範(General Data Protection

Regulation, GDPR)及相關資訊安全規範執行。

2. 企業、研究人員及各國公家單位合作，須遵守嚴格的資訊安全標準管理。
3. 個人仍保有數據的控制權。

歐洲健康資料庫為新任歐盟委員會的政見之一，於 2019 年 11 月 29 日第 16 屆數位健康網絡會議中提起討論，各成員國在該會議中尚未達成共識，具體行動規劃尚待未來接續討論。

(五) 1 百萬基金計畫(1+Million Genomes Initiative)

為促進個人化精準醫療及醫學研究發展，建立安全的健康數據庫，並支持歐盟「單一數位市場」目標，2018 年 21 個會員國共同簽署「1 百萬基金計畫」合作宣言，期望截至 2022 年歐盟將獲得至少一百萬組定序的人類基因組，其目標如下：

1. 截至 2022 年歐盟達到擁有一百萬組人類基因組(genomes accessible)。
2. 達到歐盟跨國資料流通性(linking access)及建構基因組資料庫。
3. 提供足夠規模的數據，以產出有影響力的臨床研究(new clinically impactful)。

迄今，為確認需求，連結專家網絡及各項計畫，已成立工作小組著手規劃整體計畫路境圖及行動架構。

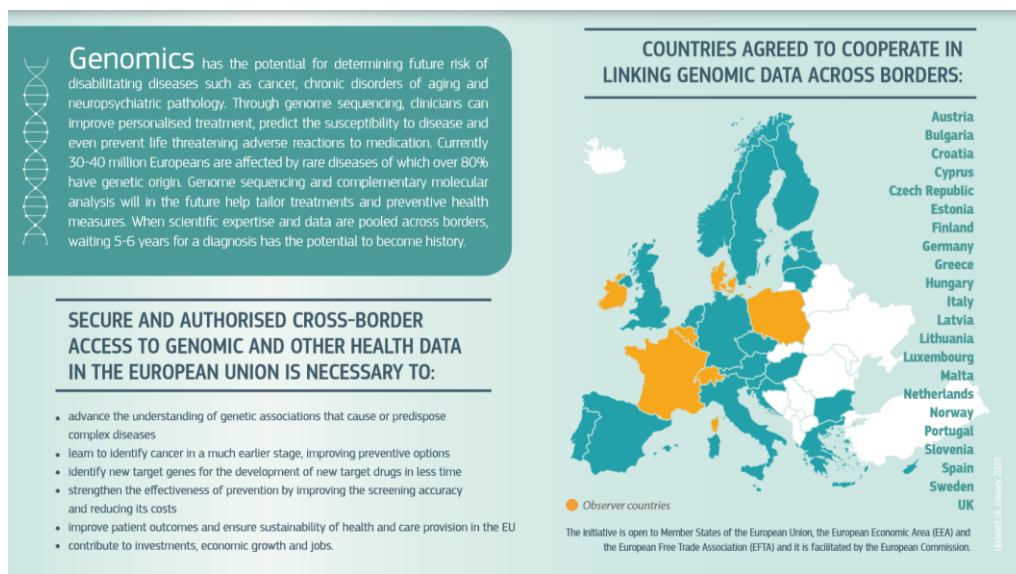


圖 7 1 百萬基金計畫

三、實習內容

本次實習安排於歐盟執委會衛生及食品安全總署(DG SANTE)的歐洲參考網絡團隊，該團隊之主責業務一歐盟參考網絡自 2017 年建立至今，已由部署、執行階段，逐步邁向監控及初步結果評估階段，其團隊共 9 人，業務包括召開參考網絡協調員 (Coordinator)會議及成員國委員會(Board of Member States)會議、5 個工作小組(分別為：研究、監測、知識建構、法律及利益關係者、整合體系)運作及開會、資通訊(Information Technology, IT)平台規劃、網絡成員提案申請及其他行政事項(如預算編列)等，實習期間主要為指定政策官(指導員)的協辦，負責的工作內容如下：

(一) 規劃歐洲參考網絡教育訓練的總體策略 (Common Strategy)

歐洲參考網絡下的知識建構工作小組(WG on Knowledge Generation and Clinical Guidelines)負責制定所有參考網絡之各項文件統一格式及知識能力的建構，其中各項文

件統一格式的部分，已初步訂定出文件分類及標準格式，分別為臨床文件、資訊性文件、活動報告、外部公開文件，實習期間經多次視訊會議，已確認上述分類、文件格式、文件行政程序及放置平台，供 24 個參考網絡運用，另，各參考網絡之知識能力建構部分，尚未充分評估執行成效，經與指導員討論，認為此工作項目可以於短期內完成至一個段落，爰規劃為本次實習的重點工作。

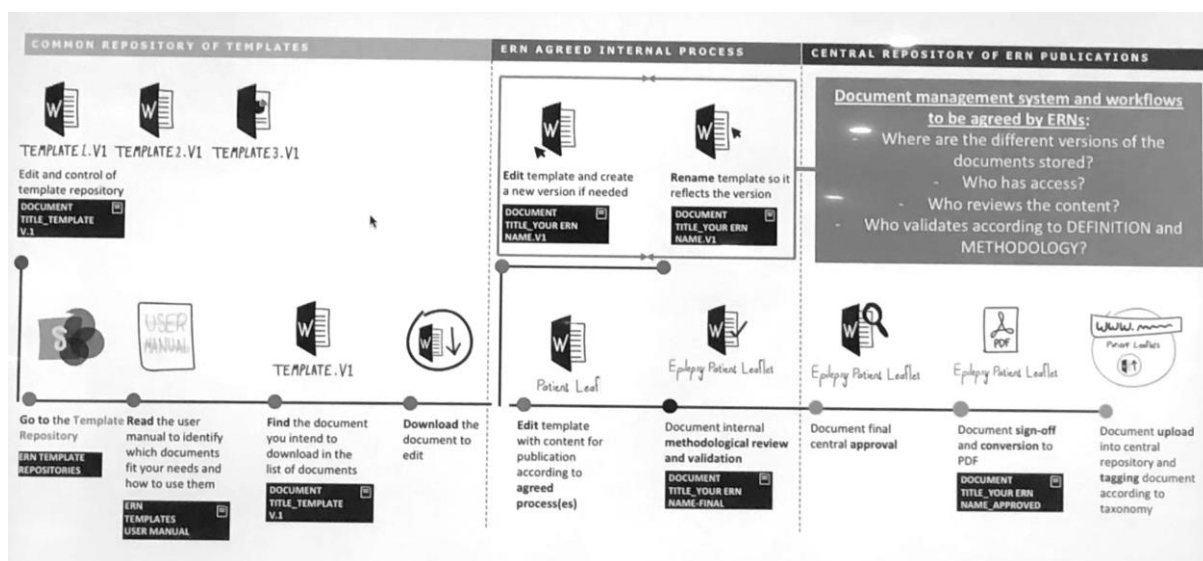


圖 8 文件行政程序(Template Document Journey)

由於歐洲參考網絡涉及對複雜或罕見疾病和病況的討論，這些疾病和病況需要高度專業化知識，然而，過去皆由各個網絡自行設計並進行教育訓練，是否確實有效地增加所有目標族群的知識能力，仍有待評估，因此，為了確認每一個參考網絡自 2018 年至今的教育訓練執行情形，了解之間的落差，提出教育訓練的總體策略，以建立有效且適當的教育框架，同時規劃建立數位教育訓練平台，職於本次實習期間整理 24 個歐洲參考網絡 2018 年至 2019 年補助計畫成果報告、網站內容、監測指標數據，參考相關教育訓練文件，提出總體策略提案，於工作小組成員內傳閱，並於 2019 年 12 月 10 日工作小組會議中進行討論達成共識，提案草案如附錄 1，會後針對此提案將成立起草小組，並於 2020 年 2 月或 3 月之工作小組會議繼續討論其具體執行規劃。

(二) 協助歐洲參考網絡電子報文章整理及編輯

公民參與為歐盟政策重要的一環，為了讓民眾更了解歐盟參考網絡，該網絡亦發行電子報(網址：https://ec.europa.eu/health/ern/newsletter_en)，內容包括：關鍵人物的訪談、焦點事件及鼓舞人心的小故事或實例，本次實習職協助該電子報總編輯徵求及整理歐盟參考網絡相關小故事及實例。

(三) 參與每週例行處務會議、ERN 團隊會議及其他相關會議

實習期間除了參與每週例行處務會議及 ERN 團隊會議外，亦參與 3 場由實習單位 B3 辦理之大型會議，ERN 醫療照護協調機構會議(ERN Coordinators Group Meeting)、ERN 成員國委員會會議(ERN Board meeting)及第 16 屆數位健康網絡會議(16th eHealth Network Meeting)，以及其他大大小小的國際會議、研討會、工作會議、視訊會議，共計 30 場，列表如附錄 2。



圖 9 會議現場(左圖為 ERN 醫療照護協調機構會議、中圖為 ERN 研究討論會議 -PaedCan assembly、右圖為 EU 血液、組織及細胞評估會議)

肆、心得與建議

NEPT 計劃為了解歐盟的政治、文化、實際社會情況及 DG SANTE 的具體工作提供了理想的機會，在三個月的時間裡，職負責該部門的一些短期任務，參加部門的各項

活動，並與同事討論歐洲參考網絡、數位健康以及相關的健康問題，由於東西方思維及不同國家思考方式的差異，不論是實習方或者實習單位皆可以從雙方那裡獲得豐富的反饋，達到雙贏。此外，職非常感謝能成為 ERN 團隊的一員，同事們皆非常友好，樂於分享經驗及為我解惑。

對我來說，這是一次寶貴的經驗，希望將來，NEPT 計畫能帶動歐盟及台灣之間更多的互動，並有機會促進臺歐健康議題之交流及合作，另本次實習中，值得借鏡之相關建議如下：

一、嚴謹的預算編列及政策評估分析，以確保政策執行成效

歐盟運作強調嚴格的監察體系及公開透明的執行方式，其預算來自於每個成員國提供該國約 1%GDP，因此，成員國皆十分關注各項政策執行的成效，每項政策推動，皆進行詳盡的文獻探討、政策評估、修訂法規、訂定標準作業程序架構及執行後的政策影響評估，以修正施政目標與執行間的差距，此外，亦著重於廣納各界意見及公民參與，上述做法，值得我國思考及學習。

二、信任管理制度，減少繁雜行政流時程，並善用視訊進行會議或工作執行

DG SANTE 對於員工充分授權，採信任的管理方式，員工於差勤系統自行登錄每日工作時數，正式職員因所掌業務之專業性，可應各界邀約對外發表演說，且該人員所準備之對外簡報內容，無需內部公文陳核，能自行決定演說內容，於其他業務處理上，亦尊重承辦人員的判斷，少有繁複的公文簽核程序，也因歐盟組織重視員工自我管理，員工享有在家辦公的權力，該員工可經由視訊參與工作內容。此外，視訊會議為歐盟辦理會議常見的進行方式之一，並善用行事曆整合及資料分享維持工作順利進行。

2020 年初受到新興傳染疾病衝擊，遠距辦公及視訊會議在世界各地蔚為風潮，如果善用此遠端工作模式除了防疫的優勢外，也是減少行政成本，降低時間及空間阻隔的

好方法，惟實際應用仍需考量 IT 技術(易操作的界面、資訊共享等)、資訊安全、人員管理(工作進度、人員溝通等)各方面完美結合，方能產生實質效益。

歐盟的工作環境，存在多元文化的包容性，尊重各界團體及不同國家的意見，雖然因國籍身分各有立場，卻能找到共通的工作模式，邁向歐盟共同的目標。職能參與本次實習機會，深入其中，實屬難得，建議衛福部及所屬各機關能將 NEPT 訓練，納入人員培訓的規劃，藉以啟發我國公部門現行工作者之不同思維，提升人員素質，進而推動更多有利國民的政策作為，為我國國民謀求更棒更健康的生活品質。

Strategy for ERNs Training and Education

1. Background

European Reference Networks (ERNs) are patient centered networks involving healthcare providers across Europe to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment, and concentrated knowledge and resources. Knowledge generation and dissemination is a key objective established by Art 12 of Directive 2011/24/EU and secondary legislation (Delegated Decision 2014/286/EU on the criteria and conditions that Networks and healthcare providers wishing to join a Network shall fulfil).

ERNs' mandate is to design a common strategy on training and education in order to establish an effective and appropriate logical framework including common goals, elements, concepts, technical support and to build an e-training system as well for building capacity among all stakeholders involved in the ERNs.

2. Previous Educational Programmes among ERNs

In order to understand gaps in education strategies, we reviewed:

- the data of the ERN core indicators¹ which were agreed by the ERN-CG and approved by the ERN Board of MS in September 2018,
- deliverables and reports on education and training activities/programs covered by the grants under the 3rd EU Health Programme⁷ (18 ERNs provided deliverables) and
- the content of the 24 ERNs websites.

After reviewing these materials, we selected and retrieved indicators and deliverables regarding education and training and summarized them into a table (see appendix 1).

This initial assessment, shows that there are already multiple training tools and educational activities and programmes promoted by the ERNs and their members. All ERN members organized several courses, developed e-training and learning materials for different target groups, transferred information and knowledge by newsletter or email to empowerment HCPs, patients and related stakeholders from 2017.

Some ERNs (such as ERN BOND, Endo-ERN, ERKNet, ERN LUNG, ERN EURO-NMD, ERN EYE, ERN GENTURIS, ERN ITHACA, MetabERN, ERN RARE-LIVER, ERN ReCONNET, ERN TRANSPLANT-CHILD) also made surveys to identify needs and gaps in the training and education. However, common believe is that

⁷ : <https://webgate.ec.europa.eu/ern/document/directoryview/2107>

the current actions/programs don't meet all potential training needs among all audiences. E-Training and e-Learning actions were developed by a reduced number of networks. The establishment of environmentally friendly training and education activities, addressing each of the target groups would need a standardised e-Training and e-Learning platform.

3. Objectives

3.1 Objectives of Needs Assessment:

- To identify unmet needs of all groups, set their priorities, and develop strategies in order to fulfil the ERNs objectives in the field of knowledge generation and training and education.
- To determine the scale and scientific quality action plans of Education and Training programs/activities. They will increase knowledge, awareness and skills among all stakeholders in the care of rare, low-prevalence and complex diseases, including patients and patient organisations in order to reduce unacceptable diagnostic delays, and to ensure the uniform use of best standards of care across Europe. Clear indicators of effective monitoring and evaluation system should be developed in these programs/activities.

3.2 Objectives of Strategies for ERNs Training and Education

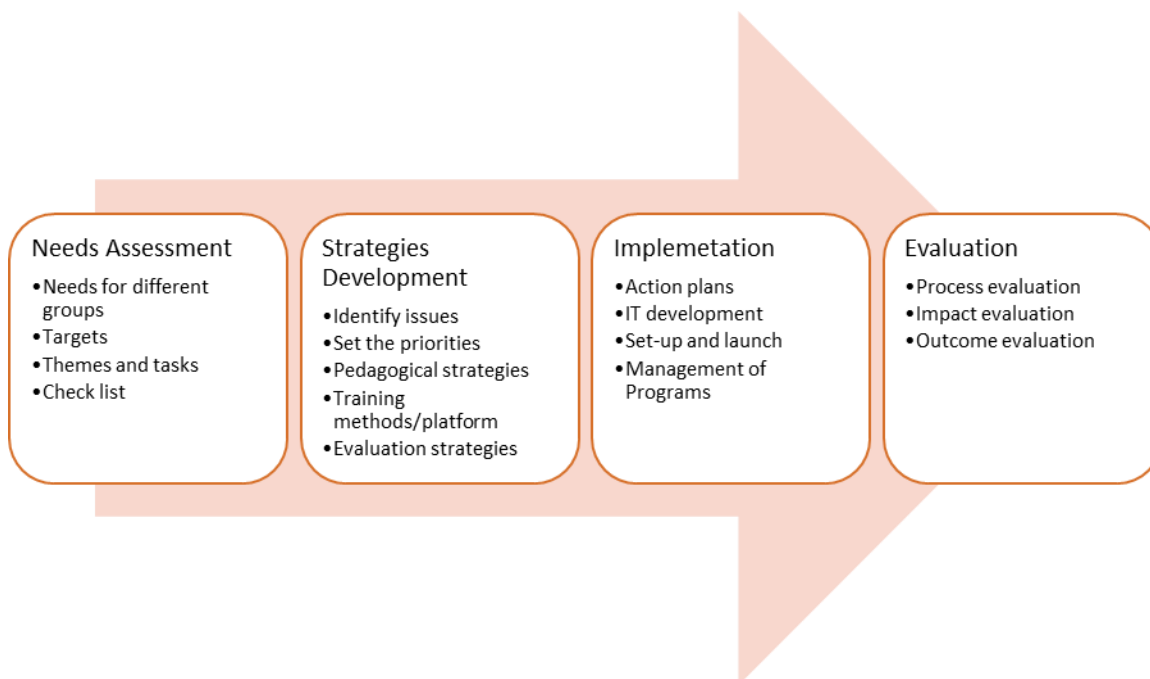
- To support the ERNs in the production of high quality training materials by providing them with the appropriated technical services and products.
- To create, adapt, develop and maintain a standardised e-Training and e-Learning environment to collect, use and disseminate the training and learning materials. The solution should be preferably an open source virtual environment (Moodle or similar).
- To develop a virtual environment that should be built taking in account the current developments and experiences already developed by the Commission in other fields of expertise (by instance, development and cooperation or research).

4. Methodology

4.1 Implementation:

- The project will be developed in two phases in a stepwise approach:
 - (1) 1 General system approach: common elements and priority.
 - (2) 24 ERNs approach: specific elements.
- In order to make sure that each ERN approach is aligned to the general system approach, fulfills the education and training objective of the strategy, and meet beneficiaries' needs, the networks should check each item using a ckecklist (see appendix 2, which based on the document of indicators written by Penelope Hawe et al.⁸).

⁸ Penelope H, Lesley K, Michelle N. Indicators to help with capacity building in health promotion. Australian: NSW Health Department; 1999.



4.2 Beneficiaries:

- (1) The European Reference Networks system (24 ERNs and 956 healthcare providers)
- (2) EU Patients and their families suffering of rare or low prevalence and complex diseases.
- (3) EU Healthcare providers and professionals dealing with patients suffering of rare or low prevalence and complex diseases, including primary and specialised healthcare providers, nursing personnel, psychologists, physical therapists, social workers, laboratory technical personnel etc.
- (4) Researchers of rare or low prevalence and complex diseases.
- (5) The member states and authorities.
- (6) University students and fellows (under- and post-graduate) and other relevant healthcare professionals to provide the principles of the clinical and multidisciplinary approach in rare or low and prevalence diseases.

4.3 Deliverables targeting different groups:

- (1) The survey questionnaire (needs, monitor)
- (2) Educational courses (symposium, workshop, course, summer/winter school, post-graduate school, CME courses, summer camp etc.)
- (3) Health communication and e-consulting network (Social media ex. twitter or similar, website, newsletter etc.)
- (4) e-Training and e-Learning management platform (Moodle or similar, Webex, APP)
- (5) e-Training and e-Learning materials (online course, webinar, video, brochure etc.)

5. Timeline

The strategies will be developed following target dates, as show in the table below. All tasks are divided into two parts: (1) New development; (2) Complete development.

Target date	Tasks	Description
Q4/2019- Q1/2020	Conceptualization	Negotiation and set up structure of strategies for ERNs training and education
Q1-Q2/2020	Need Assessment	<ul style="list-style-type: none">• Identify needs for different groups• Identify targets, themes and tasks
Q2-Q3/2020	Strategies Development	<ul style="list-style-type: none">• Identify issues• Set the priorities and pedagogical strategies• Migration Plan for Courses in the training methods/platform• Initial Moodle Setup and Test• Identify evaluation strategies
Q4/2020-Q4/2021	Implementation	<ul style="list-style-type: none">• Action plans for setting up, launching, and management of programs/activities• Selected e-learning and training material migrated in the training methods/platform
Q1-Q2/2022	Evaluation	<ul style="list-style-type: none">• Process evaluation• Impact evaluation• Outcome evaluation

Appendix 1 Previous Educational Programmes among ERNs

•The summary form in the appendix 1 doesn't collect complete data, but it shows some valid information. Moreover, since the data show broad variability and lack of information for some indicators and events, it may be bias.

•The definition of 2 ERN core indicators are as follows:

1. **Activities (represent number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organised by the ERN):** The total number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organised by the ERN within the specified time period.

2. **Webinars (represent number of educational webinars aimed at healthcare professionals delivered by the ERN):** The total number of educational webinars aimed at healthcare professionals created and delivered on an appropriate platform by the ERN within the specified time period.

	ERNs	2018		2019		Deliverables	Objectives
		Activities	Webinars	Activities	Webinars		
1	ERN BOND	31	4	42	12	1. Survey 2. Leiden E-learning laboratory 3. Leiden University Boerhaave Post-graduate School (e.g., post-graduate specialist courses, summer school, etc...)	To increase knowledge and awareness on RBDs among all stakeholders in the care of these diseases
2	ERN CRANIO	2	0	2	0	1. Exchange visits 2. Educational sessions at ERN CRANIO Annual Network Meetings	Knowledge improvement for HCP
3	Endo-ERN	0*	14*	94	132	1. 2 Survey: to Endo-ERN HCP representatives, and patients (translated from english into Spanish, Frans, Italiaans, Duits en NLs tor each more patients 2. symposium, course session, Summer/Winter School (including ESE, ESPE), Postgraduate Education Course (EASD/ISPAD/ESPE), 3 rd Preceptorships & Clinical Update on Rare Adult Solid Cancers (ESO-ESMO-RCE) 3. Online platform	1. Needs assessment 2. Focused education provided to trainees/GPs/students and concerning specific age groups 3. Focus on life-span issues & transition skills/programs 4. Focus on patients involvement (PROMs, ethical and sensitive issues) Face
4	ERN EpiCARE	0*	8*	158	0	Courses, such as 18th San Servolo Advanced Epilepsy Course	Knowledge improvement for HCP

		2018		2019			
	ERNs	Activities	Webinars	Activities	Webinars	Deliverables	Objectives
5	ERKNet	4	17	0	24	1. 17 Webinar Curriculum in 2018 2. Journal Watch (115 subscribers) 3. Case-based e-Learning Curriculum (40-50cases per year) 4. survey: attendee, satisfaction 5. ad hoc newsletter 6. 2 international CME courses	Knowledge improvement for patients, ERKNet subscribers , ESPN and ERA-EDTA membership mailing list.
6	ERN-RND	6	0	162	0	Winter schools of ERN-RND	Raise capacity at sites which have a strong interest in RND
7	ERNICA	4	0	2	0	1. Sponsoring of training conferences 2. Sponsoring of training conferences 3. e-learning/training 4. Site Visits	Knowledge improvement for HCP
8	ERN LUNG	0	2	0	4	1. Educational programme survey 2. The educational programmes list has been published online on Basecamp (ERN-LUNG Project Management Tool), ERN-LUNG Webpage and the social media Facebook and Twitter to share the information with all members	1.For more transparency, the tasks and deliverables have been reorganized into a more coherent structure 2.To decrease miscommunication between the team members, each point can be discussed easily and transparently (i.e. via message board and campfire) and in a manageable way so that all members who are interested in this specific topic have unrestricted access to all relevant information and can learn about what is happening.

	ERNs	2018		2019		Deliverables	Objectives
		Activities	Webinars	Activities	Webinars		
9	ERN Skin	0*	1*	-	-	<ol style="list-style-type: none"> 1. HCP: face-to-face training courses per year 2. above-mentioned courses recorded, and developing an e-learning of each topic 3. need assessment 4. Practical training: will be organized in the expert centers for teams willing to develop their expertise in the management of a specific disease or to develop their skills for a specific procedure 5. e-training courses in website 6. educational videos 	<ol style="list-style-type: none"> 1. Knowledge improvement for HCP 2. Identification and assessment of available practical training activities and tools – 2018-2019 3. Identification of diseases where practical training is needed – Identification of targets – Definition of ERN-Skin modules - 2019 4. Identification of teams ready to deliver on site practical training – elaboration of eligibility criteria and a questionnaire on expertise and experience - 2019 5. Identification of funding - 2020 6. Organisation of on-site practical training – 2021 7. ERN-Skin has funded educational videos in order to help to train both patients and families, but also health professionals involved in rare dermatological diseases.
10	ERN EURACAN	12*	3*	2	54	<ol style="list-style-type: none"> 1. 4th ESO-ESMO-RCE clinical update on rare adult solid cancers (29/11-1/12) 2. Training Courses*3 3. 2-yr training path for clinical oncologists website: rare cancers 4. Marie Sktodowska-Curie Action 5. Report on EURACAN training activities 6. E-learning sessions 	<p>Knowledge improvement for HCP, patients:</p> <ol style="list-style-type: none"> 1. To develop tools dedicated to nurses, all population for whom precise information is often difficult to obtain 2. To develop training courses for specialists and for the organisation of multidisciplinary tumour boards will be organized, both within countries already equipped with reference centres, with the aim to organize rare cancer management in all EU countries. 3. To organize exchange programs for fellows, specialists, and post docs within and across the different domains to disseminate specific expertise and research programs

		2018		2019			
	ERNs	Activities	Webinars	Activities	Webinars	Deliverables	Objectives
							within the ERN. 4. To focus on training needs at cross-border level, through the establishment of a cross-border education programme addressing the very specific issues arising at this scale.
11	ERN EuroBloodNet	0	1	0	0	1. Assessment of the educational needs by questionnaire 2. Repository of Sickle Cell Disease Therapeutic Patient Educational material 3. Webinars for health professionals 4. Preceptorships for health professionals carried out on HCPs sites and coordinated by ERN-EuroBloodNet experts 5. EHA and ERN-EuroBloodNet ePAG Patient Advocacy Capacity Building Meeting	1.Needs assessment 2.Knowledge improvement: patients and professionals - Make available material that may not be known to other professionals or patients. - Identify which are the educational needs within the network in order to be addressed in the coming annual work plan with the cooperation of EHA and ESH.
12	ERN eUROGEN	0	0	0	4	1, e-training outside the ERN: Eupati, Ctti, Pcori, Stanford Medicine, British Medical Journal, FasterCures Milken Institute, Patient focused medicine development, EUROPE 2. e-training inside the ERN: 1) patients: EURORDIS Patient Leadership Training, online bite-size videos, after care following surgery 2) Clinicians: ERN ITHACA Clinical Fellowship Network, involving patient representatives in training, complex case review, live video surgery	Knowledge improvement: HCP, patients
13	ERN EURO-NMD	2	3	0	6	1.Survey 2.physical course (short courses,	1.Needs assessment 2.Knowledge improvement: HCP, patients

	ERNs	2018		2019		Deliverables	Objectives
		Activities	Webinars	Activities	Webinars		
						conference, summer schools)	
14	ERN EYE	2*	0*	0	2	1. General e-Learning videos 2. Complete ERN-EYE e-Learning program for specialists and establish e-health platform 3. Survey	1.Needs assessment 2.Knowledge improvement: patients and professionals
15	ERN GENTURIS	2	0	6	0	1. The section For patients contains seven short (1-2 minutes) informative cartoon videos for patients 2. The section For health professionals contains an online referral test, pocket cards and a checklist for clinicians. 3. Online referral test 4. Survey	1.Needs assessment 2.Knowledge improvement: patients and professionals
16	ERN GUARD-HEART	24	10	24	18	1.Tools for healthcare professionals, such as APP 2.Written educational materials for patients, such as disease-specific education leaflets 3.Educational meetings for patients 4. Education materials for healthcare professionals, such as educational meeting 5. Specialized training programme for healthcare professionals (fellowship)	Knowledge improvement: patients and professionals: 1.To facilitate access to highly specialised diagnosis and treatment of rare and complex heart diseases in both adult and paediatric patients across the European Union (EU) 2.Act as a source of information for rare or low prevalence and complex diseases of the heart for patients and their families.
17	ERN ITHACA	1*	2*	102	6	1. Survey 2. Tom's Diagnostic Journey 3. Monthly member newsletter 4. Webinar	1. Needs assessment (enhancing eLearning modules) 2. Standardized steps for diagnosis and treatment 3. Knowledge improvement: patients, HCP

	ERNs	2018		2019		Deliverables	Objectives
		Activities	Webinars	Activities	Webinars		
18	MetabERN	1*	0*	0	4	1.Survey 2.presatation with problems and methods 3.subwebsite on Education and Training “clinical case of the month”, webinar access etc.	1. Needs assessment 2. Knowledge improvement: HCP
19	ERN PaedCan	1	1	4	2	1.The Hepatoblastoma educational video 2.Webinar 3.The Survivorship Educational / Awareness movie 4. fellowship programmes 5.face to face meeting	Knowledge improvement: professionals - Improve knowledge in the field - Improve skills in dealing with cancer problems as a whole - Improve knowledge of current clinical practice and state-of-the-art treatment
20	ERN RARE-LIVER	0	2	0	2	Survey	Needs assessment
21	ERN ReCONNET	0	8	2	0	1. Periodic webinars for HCPs and patients 2. Short videos on ERN ReCONNET diseases 3. Patients’ Education 4. Fellowships for short stays in ERN centres 5. Leaflets, brochures and other material on ERN ReCONNET disease 6. Formal educational activities for HCPs 7. Training on HTA and health economics 8. Webinars and on-site training for the implementation of the CPMS 9. Surveying of knowledge needs	1.Implove a community to enhance transnational cooperation between different groups to develop a comprehensive and harmonized approach to rare and complex autoimmune and hereditary connective and musculoskeletal diseases 2.Knowledge improvement: HCPs and patients

		2018		2019			
	ERNs	Activities	Webinars	Activities	Webinars	Deliverables	Objectives
22	ERN RITA	0	5	8	4	1. The pediatric rheumatology curriculum, syllabus and final exam 2. 5 educational courses in collaboration with parent societies 3. Fellowship programmes 4. Initiated activities for European knowledge based examination and certification in pediatric rheumatology 5. Face to face meeting: 2nd F2F meeting of the ERN-RITA Education WG was organized in Lisbon, 7 Sept 2018 jointly with the PReS Education and Training Committee	1. Knowledge improvement: professionals and patients 2. Initiation of the development of European subspecialty certification and knowledge based examination
23	ERN TRANSPLANT-CHILD	7	15	14	46	1. Survey 2. Online Courses and the e-learning material 3. Face to face meeting and workshop 4. Short-term Secondment Programme 5. Summer camp	1. Need Assessment 2. Knowledge improvement: medical doctors, other healthcare professionals and patients 3. Training on development of CPGs and other guidance documents to generate documents helping best clinical practice
24	VASCERN	0	4	0	34	1. OpenApp webinars (at least 11 webinars), VASCERN Days 2018 (2 days annual seminar) 2. RDWG face to face meetings 3. Pills of Knowledge (PoK) videos: Find them all here: https://vascern.eu/what-we-do/pills-of-knowledge/ 3. CPMS Workshop for ERN helpdesk experts 4. ERN IT Helpdesk Network and Meetings 5. communication tools (news and	1. Knowledge improvement: professionals, patients to improve care. 2. Assist new users in gaining accounts and initiating in CPMS 3. educate healthcare professionals, patients or the general public on the rare diseases covered by our network (raising awareness).

		2018		2019			
	ERNs	Activities	Webinars	Activities	Webinars	Deliverables	Objectives
						updated) 6. vEDS study day* –for clinicians on various topics related to vascular Ehlers-Danlos syndrome (vEDS), presentations were filmed and made into 16 Pills of Knowledge (PoK) videos! 7. Dos and Don'ts factsheets 8. "Patient pathways Patient materials translated by VASCERN (ex: Bakoumba: children's Marfan book translated from French into 6 EU languages.	

Note: - represent missing data from 2018-2019 data collection exercise; * represent missing data from 2018-2019 data collection exercise and input data which are collected from 2017-2018 data collection exercise; deliverable and objective are mainly retrieved from reports using grants, however, if the reports are missing, the information of deliverable and objective will be retrieved from websites of ERNs.

*Additional comments (from VASCERN): We have asked our members if they are interested in formal educational activities (that acquire credits) but this has not been something requested to date. We held a study day for clinicians on vEDS but no credits were given for this event. In 2019 we should have produced 34 PoK videos that are short single video lessons (of approximately 3-5 minutes long) in which an expert talks about a specific topic that has been selected and validated by the Rare Disease Working Groups (RDWGs). Our PoKs are directed at either clinicians, patients or a more general audience and we make sure that this is clearly stated.

Appendix 2 ERNs training and education checklist (Self-evaluation)

- The checklist helps you to ensure current development in carrying out training and education activities at your ERN from 2017 to 2019, and check new development in alignment with general system approach at your ERN from 2020 to 2021. Each section of the items contains strategies in training and education. Read each question and answer with YES, PARTLY or NO by circling the number under the appropriate column.
- At beginning, calculate your total score by adding together the subtotals of three columns of before the strategies launch (Current development at your ERN from 2017 to 2019) when completed the checklist.
- Then, in the evaluation stage in 2022, calculate your total score by adding together the subtotals of three columns of after the strategies launch (New development at your ERN from 2020 to 2021) when completed the checklist.
- Finally, we can illustrate before and after difference among your ERN training and education activities after the strategies launch.

		Before launching the strategy <i>Current development from 2017 to 2019</i>			After launching the strategy <i>New development from 2020 to 2021</i>		
Item		YES	Partly	No	YES	Partly	No
Session 1: Needs Assessment in Empirical basis							
1	Does the training and education program contain empirical data with regard to the health problem and problem determinants?	1	0.5	0	1	0.5	0
2	Does the training and education program contain empirical data with regard to the expected outcomes?	1	0.5	0	1	0.5	0
3	Does the training and education program contain specification of the target group characteristics, size and the channel or way of reaching these people?	1	0.5	0	1	0.5	0
4	Does the training and education program contain evidence that the target groups have been involved in this program?	1	0.5	0	1	0.5	0
Session 2: Strategies Development							
5	Does the training and education program contain concreteness of objectives, specification of strategies, and strategy objectives?	1	0.5	0	1	0.5	0
6	Does the training and education program contain clearness of the strategies or methods (including evaluation strategies) in accordance with different target groups?	1	0.5	0	1	0.5	0

	Item	Before launching the strategy <i>Current development from 2017 to 2019</i>			After launching the strategy <i>New development from 2020 to 2021</i>		
		YES	Partly	No	YES	Partly	No
7	Does the training and education program contain the design of adequate e-learning infrastructure?	1	0.5	0	1	0.5	0
Session 3: Implemetation							
8	Does the training and education program contain clearness of the planning, accuracy and detail of face-to-face training in documentation?	1	0.5	0	1	0.5	0
9	Does the training and education program contain clearness of the planning, accuracy and detail of virtual training (e-learning and e-training) in documentation?	1	0.5	0	1	0.5	0
10	Are the environment of e-training and e-learning developed and e-materials easily accessible?	1	0.5	0	1	0.5	0
11	Does the training and education program contain realism of the planning, that is, is what is being proposed feasible?	1	0.5	0	1	0.5	0
12	Does the training and education program contain evidence that the program is not overlapping with existing programs?	1	0.5	0	1	0.5	0
Session 4: Evaluation							
13	Does the training and education program contain specification of the procedures of the process evaluation?	1	0.5	0	1	0.5	0
14	Does the training and education program contain possibility to adjust the program on the basis of feedback from the process evaluation?	1	0.5	0	1	0.5	0
15	Does the training and education program contain provision for baseline, effect and follow up measurement using data sources with accepted validity	1	0.5	0	1	0.5	0
16	Does the training and education program contain a design component that will evaluate performance or contribution in each of target groups and in respect of the dimensions of impact, influence and sustainability?	1	0.5	0	1	0.5	0

Column Subtotals

附錄 2、歐盟期間參加會議列表

No.	Date	Name of Meeting
1	10/3/2019	Meeting with EURORDIS Yann le Cam (stakeholder of rare diseases)
2	10/9/2019	6th Meeting of the Representatives of the Signatories of the 1+Million Genomes Initiative
3	10/10/2019	A Look beyond 2020- Policy and Research Prospects for Healthcare Biotechnology
4	10/11/2019	European Health Data Space – Internal discussion
5	10/15/2019	6th Meeting of the ERN IT Advisory Group (ITAD Meeting)
6	10/15/2019	Meeting WG Knowledge Generation
7	10/17/2019	CROSS-BORDER HEALTHCARE EXPERT GROUP MEETING
8	10/17/2019	PaedCan assembly
9	10/23/2019	Presentation by the European Observatory "Everything you always wanted to know about the EU..."
10	10/25/2019	Preparatory WebEx on patients' pathway - Sara - ReCoNNET
11	10/28/2019	Conference on the Evaluation of The EU Legislation on Blood, Tissues and Cells
12	11/5/2019	Webex with Chafea on AMEQUIS
13	11/11/2019	catch up on cancer action with Matthias
14	11/13/2019	Workshop of the ERN Research Working Group
15	11/14/2019	ERN Coordinators Group
16	11/15/2019	ERN Board meeting
17	11/19/2019	Digital Day 2019: What does innovation cost?
18	11/21/2019	TOR AWP 2019 Health Programme
19	11/22/2019	Migration, Health, and Medicine Conference
20	11/26/2019	WG on ERN monitoring: results of the data collection exercise 2018 and 2019 and the next steps.
21	11/27/2019	Webinar on the Taxonomy and internal repository of ERNs documents
22	11/27/2019	Value of Treatment – Researchers Joint meeting on Rare Neurological Disorders case studies (RNDs) and Mental Disorders case studies

No.	Date	Name of Meeting
23	28,29-11-2019	16th eHealth Network
24	12/4/2019	Aviesan conference "Artificial intelligence and health_Antimicrobial resistance_New vaccines
25	12/5/2019	Artificial Intelligence 2019
26	12/5/2019	Rare diseases aren't rare. How can European solidarity improve the daily life of 30 million citizens?". EMRaDi is an Interreg-funded cross-border collaboration in the Euregio Meuse-Rhine
27	12/10/2019	Meeting of the Knowledge Generation WG
28	12/11/2019	Registration for ecta Regulatory Conference 2019
29	12/17/2019	Academy of Technology, Digitalisation, AI and Humanism
30	12/17/2019	CO-OPETITION IN 5G MARKETS: Innovation, Standards and IPRs