出國報告（出國類別：實習）

臺灣史丹福衛生政策學院培訓計畫

服務機關：衛生福利部國民健康署
姓名職稱：張永泓技正
派赴國家/地區：美國/加州
出國期間：112 年 7 月 29 日至 112 年 8 月 27 日
報告日期：112 年 10 月 18 日

摘要（200-300 字）

為培育我國國際衛生人才，衛生福利部與史丹福大學(下稱史大)簽署合作備忘錄，目標為強化衛生政策研究及人員培訓，拓展衛生政策管理之國際視野及專業交流，以因應各種公衛事件，本次受訓主題包含提升兒童健康照護、新興醫療科技評估、數位醫療政策、提升大流行因應整備量能等議題。

本次本署派員赴史大受訓為期 4 週，受訓主題為「低(含極低)出生體重兒居家訪視之美國經驗與創新數位化輔助之作法」，受訓期間學習美國極低出生體重兒居家照護(包含訪視、療育及支持團體等)、健康發育追蹤及後續療育服務等經驗，並分享我國早產兒居家訪視及發展追蹤之作法，未來建議可持續深化此交流機制。

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本文

一、目的:

為培育我國國際衛生人才，衛生福利部與史大簽署合作備忘錄，目標為強化衛生政策研究及人員培訓，拓展衛生政策管理之國際視野及專業交流，以因應各種公衛事件，本次受訓主題包含提升兒童健康照護、新興醫療科技評估、數位醫療政策、提升大流行因應整備量能等議題。

本次本署提報之受訓主題為「低(含極低)出生體重兒居家訪視之美國經驗與創新數位化輔助之作法」，赴史大培訓前與該校醫學院醫療預防及成果政策研究中心王智弘主任就目前業務推動情形及預計之受訓目標進行初步討論，以低(含極低)出生體重兒居家照護計畫為主題，並設定 3 個受訓目標:1. 學習美方擬定公共衛生政策推動的思考模式、2. 學習美方提升健康照護可近性及導入智慧科技等作法、3. 與美方相關專業學者建立聯繫管道並研擬未來合作之可行性。

二、過程:

(一)受訓行程:

日期	內容
7 月 29 日(六)	10:00 AM 桃園國際機場(出發) 7:00 AM 舊金山國際機場 (抵達)
7 月 31 日(一)	9:00 AM 赴史大醫療預防及成果政策研究中心報到
8 月 1 日(二)	12:00 PM~2:00 PM 專案報告及討論: 嬰兒健康與發展計畫(IHDP，Infant Health and Development Program)簡介與台灣之作法比較及討論
8 月 3 日(四)	12:00 PM~2:00 PM 專案報告及討論: 早產兒神經發展之追蹤新知 (Neurodevelopmental Follow-up of Preterm Infants: What Is New?)
8 月 8 日(二)	10:30 AM~12:00 PM 專案報告及討論: 極低出生體重兒神經發展追蹤之品質指標: 專家小組討論過程及結果(Quality-of-Care Indicators for the Neurodevelopmental Follow-up of Very Low Birth Weight Children: Results of an Expert Panel Process)
	2:30 PM~3:30 PM 前美國預防服務工作組(USPSTF, US Preventive Task Force)主席 Dr. Doug Owens 演講，演講主題「Screening for Cancer: U.S. Preventive Services Task Force Guidelines on Screening for Cancer」。
8 月 10 日(四)	12:00 PM~2:00 PM 專案報告及討論: 嬰兒健康與發展計畫對於學齡期特殊教育使用之影響(The Effect of the Infant Health and Development Program on Special Education Use at School Age)
8 月 11 日(五)	2:30 PM~4:00 PM 同王智弘主任、國衛院陳美惠醫師及疾管署鄭皓元醫師拜會史丹福 Lucile Packard 兒童醫院新生兒科及現任加州周產期品質照護協作組織(CPQCC)品質管理主席-波菲特教授(Jochen Profit, MD, MPH)，參觀新生兒加護病房及討論加州新生兒加護及早產兒追蹤品質等議題
8 月 14 日(一)	2:30 PM~3:30 PM 同王智弘主任、疾管署鄭皓元醫師及資訊處吳祐綺設計師與 Stratus Medicine 營運長 Dr. David Burdick 討論台灣 PHIR 發展及展望
8 月 15 日(二)	12:00 PM~2:00 PM 專案報告及討論: 影響極低出生體重早產兒第一次回診之因素探討: 以加州為例(Factors Associated with Successful First High-Risk Infant Clinic Visit for Very Low Birth Weight Infants in California)
8 月 17 日(四)	12:00 PM~2:00 PM

	專案報告及討論: 簡介及分享我國推動低(含極低)出生體重兒居家照護及相關單位推動早產兒追蹤計畫
8 月 18 日(五)	12:00 PM~2:00 PM 專案報告及討論: 綜整在史大期間之專案報告及交流討論之重點及未來展望
8 月 22 日(二)	12:00 PM~2:00 PM 王智弘主任邀請史丹福大學醫學院衛生政策教授所羅門（Dr. Joshua Salomon 演講公共衛生政策模型建構(Modeling for Public Health Policy)
8 月 24 日(四)	5:00 PM~5:30 PM 專案報告及討論: A Testing and Quarantine Algorithm for Individual International Travelers Using Published Data on WHO-Approved Vaccines and Bayes’ Theorem
8 月 26 日(六)	1:00 PM 舊金山國際機場 (返程)
8 月 27 日(日)	5:00 PM 桃園國際機場 (抵達)

(二)受訓討論重點總結:

本次本署派員受訓主要為更佳了解美國針對早產兒與極低出生體重兒追蹤及訪視之政策推動之作法，在受訓期間與史大王智弘主任及相關專家針對下列主題進行探討:

1. **早產兒出院返家後的介入計畫: 嬰兒健康與發展計畫(IHDP，Infant Health and Development Program)**

   本計畫為一多重地點(共在全美 8 個醫學中心推動)、隨機分派之研究計畫(隨機分派 1/3 至介入組；2/3 至對照組)，此計畫目的為透過以家庭及中心為基礎的介入措施，強化低出生體重兒(Low birth weight，LBW，出生體重小於等於 2,500g，此類兒童為神經學發展問題之高風險群)的認知及行為表現，此計畫為羅伯特·伍德·約翰遜基金會（Robert Wood Johnson Foundation)資助之計畫，其介入內容包含 1.高密度的居家訪視(1 歲前每週 1 次；2-3 歲每 2 週 1 次)，訪視內容諸如:提供照顧者情緒、社會及照顧技巧上的支持(包含:家長問題解決課程，提供系統性策略以利家長處理生活相關問題)、提供兒童發展重要時程相關資訊(包含:教導照顧者有關適當發展月齡的遊戲及活動，以利其在日常生活中與兒童互動)、指導照顧者如何強化兒童的認知、語言、身體及社會化能力的發展、協助照顧發展上有問題及脆弱兒童。2.以中心為基礎的早期教育計畫: 服務介於矯齡 1 歲至 3 歲的兒童，並提供必要的交通協助，師生比較低(較小兒童 1:3、較大兒童 1:4)；每次團體教育人數 6-8 人。3. 家庭支持團體等，並配合出院後定期追蹤。其結果顯示相對於對照組(僅有出院後定期追蹤)，介入組在 3 歲時的智力發展表現較佳，然此效果在其至 5 歲、8 歲及 18 歲時評估則逐漸減少且已無顯著差異，僅在較重低出生體重兒(heavier LBW)在 5 歲及 8 歲時仍較對照組佳；另外在學業成就上，較重低出生體重兒在數學及語言等表現較對照組佳。此計畫價值為提供高密度的介入服務，並進行長期追蹤(追蹤至 18 歲)，具有重要的研究價值，並可從其一系列文獻中了解在早產兒及其家庭出院後的早期介入服務，對於兒童發展具有長遠的影響。

2. **早產兒神經發展追蹤計畫: 加州兒童服務(California Children Service, CCS)與加州周產期品質照護協作組織(California Perinatal Quality Care Collaborative, CPQCC)共同合作之高風險嬰兒追蹤計畫(High risk infant program，HRIF)**

   加州兒童服務(CCS)為加州健康服務部門(California Department of Health Services, DHS)轄下兒童醫療服務單位(Children’s Medical Services Branch)推動之服務，其服務對象為 21 歲以下、設籍於加州、有醫療及經濟問題之族群，其服務範圍涵蓋層面廣泛，包含針對兒童之特殊醫療照護、特殊照護中心、門診手術、追蹤照護、藥物及相關補給、醫療設備、專業護理等，其中特殊照護中心包含: 高風險嬰兒追蹤計畫(High risk infant program，HRIF)、新生兒加護病房、兒科加護病房、復健中心及移植中心等。

   加州周產期品質照護協作組織(CPQCC)成立於 1997 年，係全美第一個以州為單位的強化周產期照護組織，藉由發展一包含公、私立婦產科及新生兒科健康照護提供者、保險者、公共衛生專業人員等支持的協作網絡，進而強化組織成員間的標竿學習及相關品質促進活動等，以增進加州之周產期健康照護品質及結果。該組織擴展福佛特牛津網絡(Vermont Oxford Network)數據庫架構，建立以州為單位之數據庫，並聚焦於品質精進而非發展隨機分派試驗。該組織任務為有三，其一

為蒐集高品質之數據；其二為將數據轉譯為可運用於發展經風險校正且即時的分析報告，以利後續成員之工作進展；其三為推展行動措施，以支持周產期健康照護之工作者持續精進周產期照護及結果。

高風險嬰兒追蹤計畫(HRIF)係加州州政府兒童服務(California Children Services ，CCS)所補助的高風險嬰兒追蹤計畫，此一計畫目的為提供出生體重兒小於等於 1,500g 或未達 32 週嬰兒或出生體重大於 1,500g 但具有特定健康情形之嬰兒出院後的定期追蹤、評估及轉介其所需要之服務(如早療)，在加州兒童服務合約醫院之新生兒加護病房(NICU)被規定皆須轉介符合收案條件之個案至此高風險嬰兒追蹤計畫(High risk infant follow-up，HRIF)，執行此計畫之單位需要有跨專業之團隊成員，包含:醫療主任、HRIF 協調人、眼科醫師、聽力師、社工師及可執行發展評估者(如兒科醫師、無理治療師、職能治療師或心理師等)，並在其出院後至 3 歲前分別於在 4-8 個月間；12-16 個月間及 18-36 個月間提供 1 次，共計 3 次的標準診察(standard visit)，診察內容包含完整生理(用藥)診察與疾病史評估、發展評估、聽力視力評估、家庭評估、家庭社會心理評估等，另亦由該州居家健康部門(home health agency nurse，HHA)認可之居家護理師，在 HRIF 團隊評估個案有其需要時，於 1 歲前提供至多 2 次居家訪視服務，其居家訪視主要目的為評估兒童居家環境安全、評估家長與嬰兒間之互動、對早產兒照護、發展及特殊需求了解程度等。

由於早產兒早期的神經發展對於未來的學習及成就有著至關重要的影響，應及早返診評估早產兒的各項發展程度，並在發現評估異常時及早轉介後續早期療育，然研究發現所有被 HRIF 計畫收案的個案，於出院後的一次返診出席率僅 76%，進一步探究影響個案家屬缺席返診的重要因子，主要與社會因子(如母親年齡、種族)、交通距離及 HRIF 執行單位服務案量有關。透過本次專案報告，了解到追蹤計畫的重點在於各項服務彼此銜接，及如何透過資料分析掌握缺席回診的高風險族群，為其制定相關策略以強化其回診意願，例如:因本計畫發現交通距離越遠者其返診的情形越差，也許可透過及早預約、提供其必要之交通補助或轉介至離個案家較近之執行單位等作法以提升其回診意願。另，透過與波菲特教授討論也了解到一計畫之品質精進需透過持續數據蒐集及分析、發現及確認執行的問題並設計介入方案及並印證介入之成效，透過數據導向(data-driven)的品質精進作為，持續優化計畫內容及品質。

3. **極低出生體重兒神經發展追蹤之品質指標**: 專家小組討論過程及結果，王智弘主任為此篇文獻之作者，其表示在當時並無系統性的極低出生體重兒神經學發展照護指標，故該團隊透過文獻回顧及調整之德菲法取得此領域專家之共識，發表極低出生體重兒在 6 歲以前應追蹤之指標及內容，共計納入一般照護(general care)，包含出生體重、頭圍、新生兒代謝性檢查、聽力篩檢、視網膜檢查、腦部超音波檢查等)；生理健康(physical health)，包含嬰兒猝死症候群衛教、菸害防制衛教、移除管路衛教等；視力、聽力、語言追蹤檢查、異常轉介、確診介入(Vision, Hearing, and Speech and Language)；發展及行為評估(Developmental and Behavioral Assessment)及社會心理學評估(Psychosocial Assessment)等 5 大領域、70 項品質指標，值得注意的是共有 58 項指標都屬於預防性照護措施。另外，作者亦指出多數極低出生體重兒會被納入 Medicaid (低收入戶政府醫療補助計畫)，但過去有文獻指出納入

Medicaid 者其獲得的照護品質較一般商業保險者差，建議聯邦政府可要求州政府提供有品質的追蹤照護及評估。一般而言一般兒科診所照護到極低出生體重兒的機率不高，可能較難注意到其神經發展追蹤之重要性及風險，其建議可運用品質精進技巧教育服務提供者及發展評量及回饋系統以強化極低出生體重兒追蹤照護等作法，另強化初級照護兒科醫師及兒科各項次專科、社福體系、教育體系間的連結，藉由資訊、數據整合及監測方可使研究者或政府研擬介入方案，並持續了解其對提升照護品質是否有影響。

4. **借鏡美國早產兒追蹤作法，反思台灣早產兒追蹤制度的未來:**

在了解加州周產期品質照護協作組織(California Perinatal Quality Care Collaborative, CPQCC)對早產兒追蹤之作法後，深刻了解到提升早產兒追蹤照護品質的第一步是高品質、可持續的數據監測機制，高品質的數據才能產生有用的資訊，這些資訊可反映早產兒追蹤照護過程的各種結果。最終，才有機會產出品質改善方案及行動，並持續監測。

我國早產兒追蹤相關議題有許多單位共同關注及投入，如早產兒基金會早於 1993 年即推動「極低出生體重出院後追蹤檢查」，有逾八成的極低出生體重早產兒獲得追蹤檢查；本署自 2021 年起亦推動「低(含極低)出生體重兒居家照護計畫」，鼓勵接生醫院之專業團隊提供早產兒家庭於早產兒返家後的專業衛教支持，提供居家訪視、視訊訪視、電話訪視及專線等服務，除希望可降低早產兒家庭返家照顧上的焦慮感外，亦希望可透過多元訪視服務追蹤及提醒早產兒相關的檢查(如:極低出生體重早產兒心智發展檢查)，以強化檢查回診率；另，新生兒科醫學會亦自 2016 年起推動台灣新生兒聯合醫療網絡(Taiwan Neonatal Network, TNN)，定期蒐集新生兒住院期間相關數據，並定期分析，並據以制定品質改善措施。因此運用 CPQCC/CMQCC 數據中心的照護品質框架，盤點了我國不同部門或組織目前運行的早產兒照護及追蹤相關方案，未來這些方案可針對服務及數據等面向進行合作及交流。

三、心得及建議:

感謝衛福部提供如此珍貴之機會至全球有名之大學進行短期進修，另亦感謝史丹福大學王智弘教授百忙中仍悉心指導，在受訓期間可感受到教授安排之閱讀素材應與後續將交流之專家息息相關。另邀請該校在各領域之重要專家與我們線上或實體討論，並時時提醒大家除自身業務外，亦可參加其他學員之業務探討。除原先設定赴史大交流目標包含建立業務所需之人脈，在史大受訓期間亦持續加強自己對於自身業務了解之深度及廣度。

本次進修了解到史大交流資源豐富，在史大醫療預防及成果政策研究中心服務之教授在健康政策各領域皆有長足的涉獵，未來可持續深化此種進修模式。另，建議持續洽邀相關單位專家(如 CPQCC)來台分享美方之作法，單位在薦派同仁出國受訓前可先盤點單位內可與史大交流之議題，亦可先與史大教授視訊討論預計進修之議題，並介紹台灣目前做法及未來可精進之處，以利赴史大交流時教授可提供美方更適切的交流機會，另外，赴史大與重要人物交流時，亦可與單位共同視訊討論以強化交流。

附錄一、受訓照片

	圖 1. 拜會史丹福大學兒科教授波菲特（Jochen Profit），左 2。
	圖 2. 定期團體討論
	圖 3. 史大醫療預防及成果政策研究中心報到及合影

	圖 4. 史大醫療預防及成果政策研究中心研究室
	圖 5.與前美國預防服務工作組(USPSTF, US Preventive Task Force)主席 Dr. Doug Owens 合影

附錄二、受訓綜整簡報

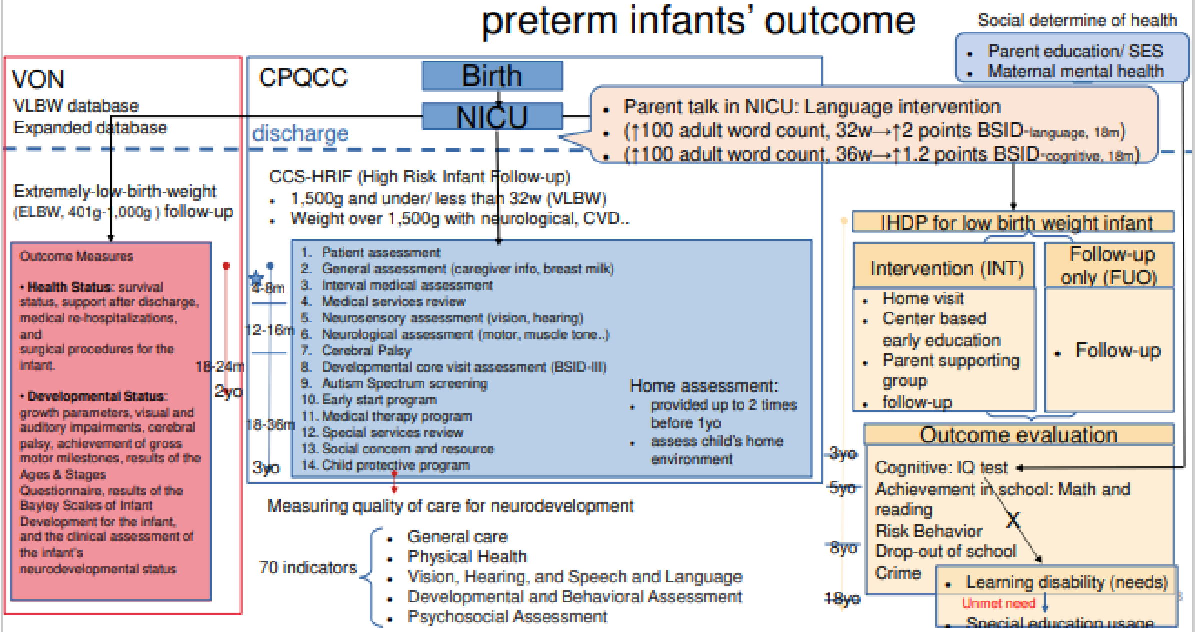
MoHW scholar report on “Home visit and follow-up programs for preterm infants”

Yung-Hung Chang

Outline

1. The U.S. approaches (intervention and follow-up) to measure and improve preterm infants’ outcome
2. The issues of Taiwan’s current projects
3. Future work

The U.S. approaches to measure and improve preterm infants' outcome



Social determine of health
- Parent education/ SES
- Maternal mental health

VON
VLBW database
Expanded database

Extremely-low-birth-weight (ELBW, 401g-1,000g) follow-up

Outcome Measures

- **Health Status**: survival status, support after discharge, medical re-hospitalizations, and surgical procedures for the infant.
- **Developmental Status**: growth parameters, visual and auditory impairments, cerebral palsy, achievement of gross motor milestones, results of the Ages & Stages Questionnaire, results of the Bayley Scales of Infant Development for the infant, and the clinical assessment of the infant's neurodevelopmental status

18-24m
2yo

CPQCC
Birth
NICU
discharge

- Parent talk in NICU: Language intervention
- (↑100 adult word count, 32w→↑2 points BSID-language, 18m)
- (↑100 adult word count, 36w→↑1.2 points BSID-cognitive, 18m)

CCS-HRIF (High Risk Infant Follow-up)
- 1,500g and under/ less than 32w (VLBW)
- Weight over 1,500g with neurological, CVD..

4-8m
12-16m
18-36m
3yo

1. Patient assessment
2. General assessment (caregiver info, breast milk)
3. Interval medical assessment
4. Medical services review
5. Neurosensory assessment (vision, hearing)
6. Neurological assessment (motor, muscle tone..)
7. Cerebral Palsy
8. Developmental core visit assessment (BSID-III)
9. Autism Spectrum screening
10. Early start program
11. Medical therapy program
12. Special services review
13. Social concern and resource
14. Child protective program

Home assessment:
- provided up to 2 times before 1yo
- assess child's home environment

Measuring quality of care for neurodevelopment

70 indicators
- General care
- Physical Health
- Vision, Hearing, and Speech and Language
- Developmental and Behavioral Assessment
- Psychosocial Assessment

IHDP for low birth weight infant

Intervention (INT)	Follow-up only (FUO)
Home visit Center based early education Parent supporting group follow-up	Follow-up

Outcome evaluation
3yo
5yo
8yo
18yo

Cognitive: IQ test
Achievement in school: Math and reading
Risk Behavior
Drop-out of school
Crime

- Learning disability (needs)

Unmet need

- Special education usage

Intervention that improves preterm infants' outcome: IHDP

IHDP (Infant Health and Development Program) for low birth weight infant: multi-site, RCT		
item	**frequency**	**Service contents**
Home visit	1/week: discharge-1yo; 1 /2 weeks: 1yo-3yo	- Emotional, social, and practical support; - Developmentally timed information about child development - Guidance in how to promote their child's intellectual, physical, and social development - Help in caring for a developing and, initially, vulnerable child
Center based early education	beginning at age 1 year (at least 4 hr a day for 5 days a week) and terminating at age 3 years	a systematic educational program provided in specialized child development centers
Parent supporting group	1 /2 weeks: 1yo-3yo	provided information about health and safety, child rearing, and other parenting concerns.
Follow-up (both intervention/ control)		

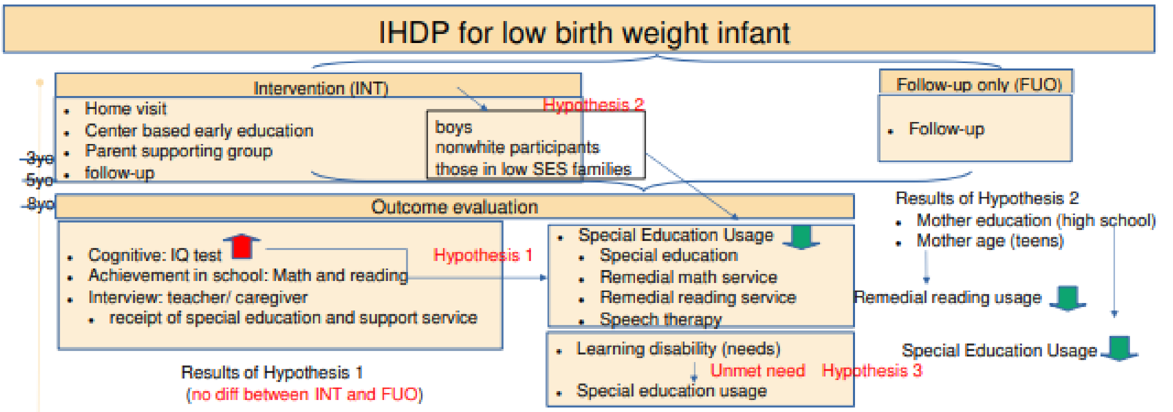
Cognitive function (INT vs CON)

	IQ combined	IQ HLBW	IQ LLBW	Achievement (HLBW) Receptive vocab	Achievement (HLBW) Math	Achievement (HLBW) Reading	Risk Behavior (HLBW) (INT vs CON)
3yo	10*	14*	7*				
5yo	-	4*	-				-
8yo	-	4*	-	6.7*	4.5*	-	-
	-	-	-	3.8*	5.1*	-	-0.7*

HLBW infants would be benefit most from the IHDP intervention.

HLBW: 2,000g-2,499g
LLBW: <2,000g

IHDP secondary analysis: Effects of IHDP intervention on special education usage



IHDP for low birth weight infant

Intervention (INT)

- Home visit
- Center based early education
- Parent supporting group
- follow-up

Hypothesis 2

boys
nonwhite participants
those in low SES families

Follow-up only (FUO)

- Follow-up

Results of Hypothesis 2

- Mother education (high school)
- Mother age (teens)

Outcome evaluation

- Cognitive: IQ test ⬆
- Achievement in school: Math and reading
- Interview: teacher/ caregiver
  - receipt of special education and support service

Hypothesis 1

- Special Education Usage ⬇
  - Special education
  - Remedial math service
  - Remedial reading service
  - Speech therapy

Remedial reading usage ⬇

Special Education Usage ⬇

- Learning disability (needs)

Unmet need Hypothesis 3

- Special education usage

Results of Hypothesis 1
(no diff between INT and FUO)

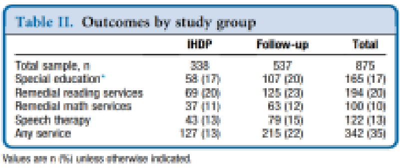


Table II. Outcomes by study group

	IHDP	Follow-up	Total
Total sample, n	338	537	875
Special education*	58 (17)	107 (20)	165 (17)
Remedial reading services	69 (20)	125 (23)	194 (20)
Remedial math services	37 (11)	63 (12)	100 (10)
Speech therapy	43 (13)	79 (15)	122 (13)
Any service	127 (13)	215 (22)	342 (35)

Values are n (%) unless otherwise indicated.

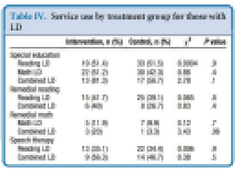


Table IV. Service use by treatment group for those with LD

Results of Hypothesis 3
(no diff between INT and FUO)

- Service usage for those with LDs was low

California: CCS-CPQCC-HRIF
Factors associates with successful 1st HRIF clinic visits

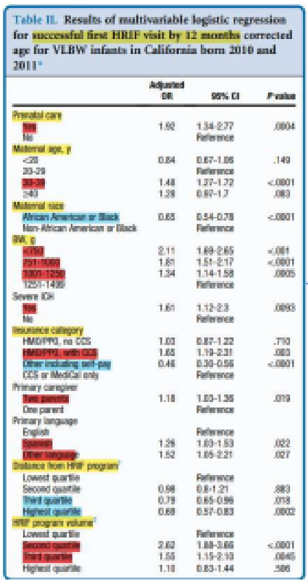
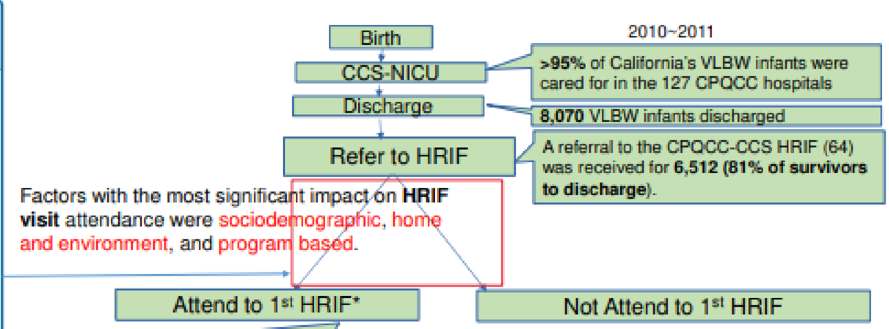


Table II. Results of multivariable logistic regression for successful first HRIF visit by 12 months corrected age for VLBW infants in California born 2010 and 2011*

	Adjusted OR	95% CI	P value
Prenatal care			
Yes	1.92	1.34-2.77	.0004
No		Reference	
Maternal age, y			
<20	0.84	0.67-1.06	.149
20-29		Reference	
30-39	1.48	1.27-1.72	<.0001
≥40	1.28	0.97-1.7	.083
Maternal race			
African American or Black	0.65	0.54-0.78	<.0001
Non-African American or Black		Reference	
BW, g			
≤750	2.11	1.69-2.65	<.001
751-1000	1.81	1.51-2.17	<.0001
1001-1250	1.34	1.14-1.58	.0005
1251-1499		Reference	
Severe ICH			
Yes	1.61	1.12-2.3	.0093
No		Reference	
Insurance category			
HMO/PPO, no CCS	1.03	0.87-1.22	.710
HMO/PPO, with CCS	1.65	1.19-2.31	.003
Other including self-pay	0.46	0.30-0.56	<.0001
CCS or MediCal only		Reference	
Primary caregiver			
Two parents	1.18	1.03-1.36	.019
One parent		Reference	
Primary language			
English		Reference	
Spanish	1.28	1.03-1.53	.022
Other language	1.52	1.05-2.21	.027
Distance from HRIF program†			
Lowest quartile		Reference	
Second quartile	0.98	0.8-1.21	.883
Third quartile	0.79	0.65-0.96	.018
Highest quartile	0.69	0.57-0.83	.0002
HRIF program volume‡			
Lowest quartile		Reference	
Second quartile	2.62	1.88-3.66	<.0001
Third quartile	1.55	1.15-2.10	.0045
Highest quartile	1.10	0.83-1.44	.506



Birth

CCS-NICU

Discharge

Refer to HRIF

2010~2011

>95% of California's VLBW infants were cared for in the 127 CPQCC hospitals

8,070 VLBW infants discharged

A referral to the CPQCC-CCS HRIF (64) was received for **6,512 (81% of survivors to discharge)**.

Factors with the most significant impact on **HRIF visit** attendance were sociodemographic, home and environment, and program based.

Attend to 1st HRIF*

Not Attend to 1st HRIF

4,938 (**61%** of survivors to discharge, and **76%** of those referred)

*Definition: At least 1 HRIF visit was completed by 12 months corrected age

Reason for not attend	%
a client not seen form was not filed	5% (82)
"no show/reason unknown" or "lost"	33%
"unable to contact"	27%
family moved or referred to another program	13%
parent refusal	6%
Insurance authorization concerns	7%

Vermont Oxford Network

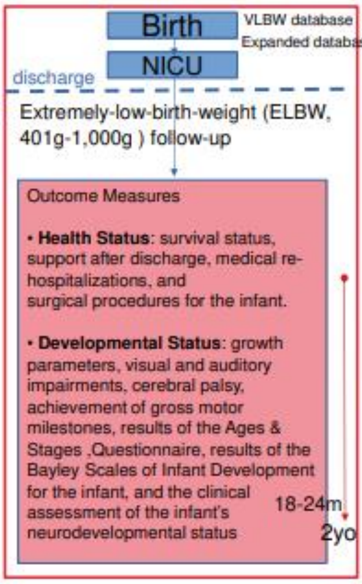
ELBW (extreme low birth weight) Follow-up Project

- The Vermont Oxford Network (VON) ELBW Infant Follow-up Study Group is a voluntary group of follow-up clinics collaborating to benchmark ELBW clinical outcomes through 2 years ca and improve both follow-up care and the value of follow-up services for ELBW infants and their families.

SUPPLEMENTAL TABLE 5 Follow-Up Trend by Year

Y of Birth	Seen in HRIF Number	%
2006	608 of 1344	45.2
2007	673 of 1556	43.3
2008	644 of 1400	46.0
2009	728 of 1637	44.5
2010	798 of 1729	46.2
2011	729 of 1666	43.8
2012	693 of 1510	45.9
2013	664 of 1506	44.1
2014	715 of 1673	42.7
2015	765 of 1863	42.1
2016	879 of 1750	50.2
2017	804 of 1869	43.0

44.7% (range 31.1–63.3) were seen in HRIF



Extremely-low-birth-weight (ELBW, 401g-1,000g) follow-up

Outcome Measures

- **Health Status**: survival status, support after discharge, medical re-hospitalizations, and surgical procedures for the infant.
- **Developmental Status**: growth parameters, visual and auditory impairments, cerebral palsy, achievement of gross motor milestones, results of the Ages & Stages Questionnaire, results of the Bayley Scales of Infant Development for the infant, and the clinical assessment of the infant's neurodevelopmental status

Very Low Birth Weight Database

Data Items

- Birth location, weight and head circumference, birth defects, maternal characteristics
- Delivery and initial resuscitation
- Respiratory care/ Surgery
- Mortality and neonatal morbidities
- Status at discharge including human milk feeding and respiratory support
- Length of stay

Expanded Database

Data Items

- Hypoxic-ischemic encephalopathy, seizures, therapeutic hypothermia, meconium aspiration
- Other items are same as VLBW database

Extremely Low Birth Weight Follow-Up

Data Items

- Health status
- Living situation
- Support after discharge
- Medical and surgical re-hospitalizations
- Growth, vision, and hearing
- Developmental status, cerebral palsy, gross motor milestones

Quality of follow-up care indicators for evaluating the process and outcome of VLBW infant

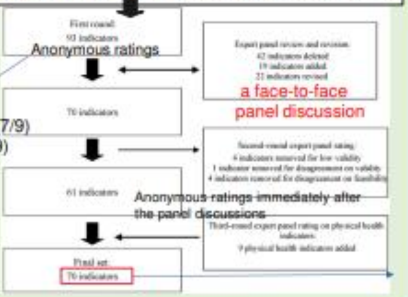
Development process

PubMed database from Jan 1966 through Mar 2003.
(key words: LBW, NICU graduates, NICU follow-up, quality of care for VLBW)

Draft indicator criteria:
1.It measured an intervention or a treatment with potential health benefits for the patient,
2. it was supported by adequate scientific evidence or professional consensus
3. it covered care that is under the control or influence of the health care provider or organization
4.it covered information that typically is found in the medical records

Modified Delphi method

Based on validity(7/9) and feasibility (4/9)



First round: 93 indicators

Anonymous ratings

Expert panel review and revision: 42 indicators deleted, 19 indicators added, 22 indicators revised

a face-to-face panel discussion

70 indicators

Second-round expert panel rating: 4 indicators removed for low validity, 1 indicator removed for disagreement on validity, 4 indicators removed for disagreement on feasibility

61 indicators

Anonymous ratings immediately after the panel discussions

Third-round expert panel rating on physical health indicators: 9 physical health indicators added

Final set: 70 indicators

Indicator contents

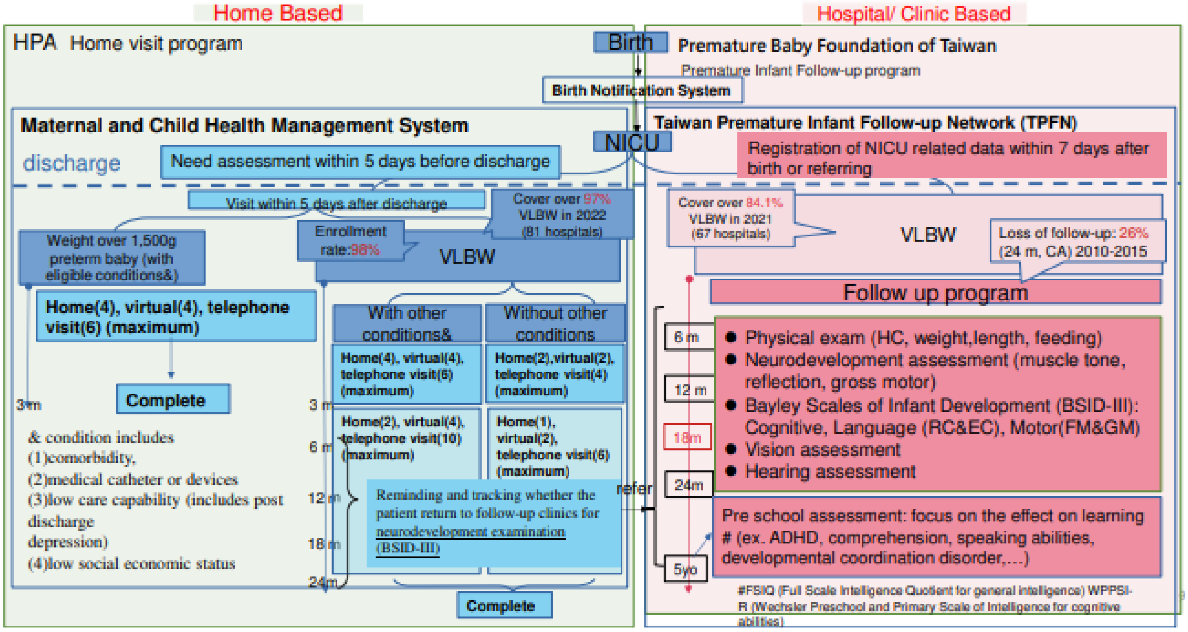
5 areas	1. general care (19 indicators) 2. physical health (9 indicators) 3. vision, hearing, speech, and language (18) 4. developmental and behavioral assessment (19 indicators) 5. psychosocial issues (5 indicators)

	Indicators n(%)
Type of care	
Preventive	[illegible]
Acute	[illegible]
Chronic	[illegible]
Function	
Screening	[illegible]
Diagnosis	[illegible]
Treatment	[illegible]
Follow-up	[illegible]
Modality	
Medical history	[illegible]
Physical examination	[illegible]
Tests/evaluations	[illegible]
Interventions	[illegible]
Return or referral	[illegible]
Applicable age	
0-1	[illegible]
1-2	[illegible]
2-3	[illegible]
3-6	[illegible]

- include primary interventions such as immunizations or injury prevention counseling.
- relate to the spectrum of care for conditions that have a time-limited course
- apply to conditions that last 3 months or more and cause significant morbidity

Quality of evidence:
(1)Level I: randomized controlled trials (2 indicators) ,
(2)Level II: non-randomized controlled trials, cohort or case control study or multiple time series (5 indicators)
(3)Level III: descriptive study or expert opinion. (63 indicators)

VLBW infant home visit and follow-up in Taiwan



Home Based

Hospital/ Clinic Based

HPA Home visit program

Birth

Birth Notification System

NICU

Maternal and Child Health Management System

discharge

Need assessment within 5 days before discharge

Visit within 5 days after discharge

Cover over 97% VLBW in 2022 (81 hospitals)

Enrollment rate:98%

VLBW

Weight over 1,500g preterm baby (with eligible conditions&)

Home(4), virtual(4), telephone visit(6) (maximum)

Complete

3 m

& condition includes
(1)comorbidity,
(2)medical catheter or devices
(3)low care capability (includes post discharge depression)
(4)low social economic status

With other conditions&

Without other conditions

3 m

Home(4), virtual(4), telephone visit(6) (maximum)

Home(2),virtual(2), telephone visit(4) (maximum)

6 m

Home(2), virtual(4), telephone visit(10) (maximum)

Home(1), virtual(2), telephone visit(6) (maximum)

12 m

18 m

24 m

Reminding and tracking whether the patient return to follow-up clinics for neurodevelopment examination (BSID-III)

refer

Complete

Premature Baby Foundation of Taiwan

Premature Infant Follow-up program

Taiwan Premature Infant Follow-up Network (TPFN)

Registration of NICU related data within 7 days after birth or referring

Cover over 84.1% VLBW in 2021 (67 hospitals)

VLBW

Loss of follow-up: 26% (24 m, CA) 2010-2015

Follow up program

6 m

12 m

18m

24m

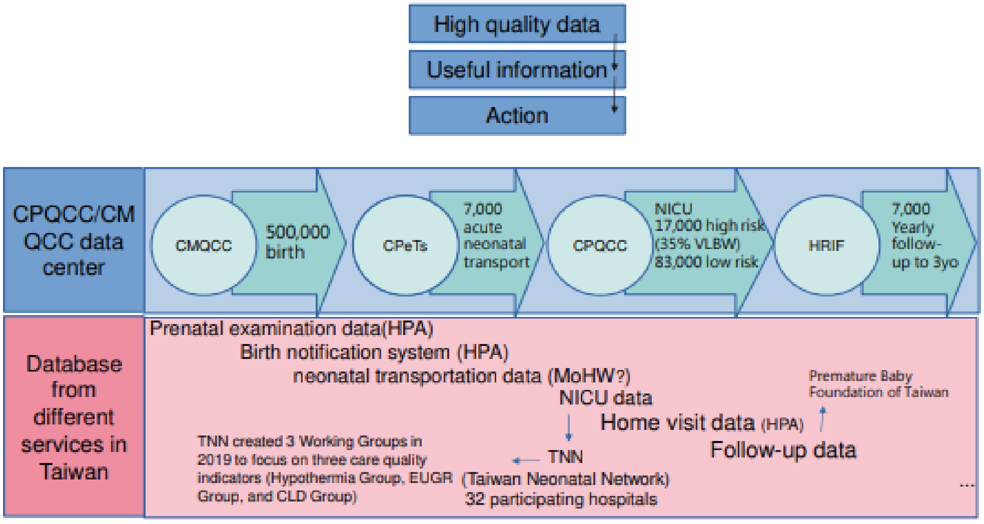
5yo

- Physical exam (HC, weight,length, feeding)
- Neurodevelopment assessment (muscle tone, reflection, gross motor)
- Bayley Scales of Infant Development (BSID-III): Cognitive, Language (RC&EC), Motor(FM&GM)
- Vision assessment
- Hearing assessment

Pre school assessment: focus on the effect on learning # (ex. ADHD, comprehension, speaking abilities, developmental coordination disorder,…)

#FSIQ (Full Scale Intelligence Quotient for general intelligence) WPPSI-R (Wechsler Preschool and Primary Scale of Intelligence for cognitive abilities)

The issues of Taiwan's current projects



High quality data

Useful information

Action

CPQCC/CMQCC data center

CMQCC

500,000 birth

CPeTs

7,000 acute neonatal transport

CPQCC

NICU
17,000 high risk (35% VLBW)
83,000 low risk

HRIF

7,000 Yearly follow-up to 3yo

Database from different services in Taiwan

Prenatal examination data(HPA)

Birth notification system (HPA)

neonatal transportation data (MoHW?)

NICU data

Home visit data (HPA)

Follow-up data

Premature Baby Foundation of Taiwan

TNN (Taiwan Neonatal Network) 32 participating hospitals

TNN created 3 Working Groups in 2019 to focus on three care quality indicators (Hypothermia Group, EUGR Group, and CLD Group)

…

Future work

1. Establishing a nationwide quality improvement collaborative, recruits Taiwan Society of Neonatology (Taiwan Neonatal Network), Taiwan Pediatric Association, Premature Baby Foundation of Taiwan, public health professionals and government officials etc.
    - Exchanging data among different programs.
    - Identifying the quality of care indicators.
    - Measuring outcomes (especially for follow-up)
    - Improving the quality of care by peer comparison, benchmarking and performance improvement activities.
2. Increasing parents engagement (talk) during NICU stay.
3. Changing follow-up strategy for motor impairment (CP→DCD)
4. Addressing the impact of maternal education, mental health, and parental SES to preterm infants' health and development.
5. Intensive early education (center-based) for VLBW from 1~3yo (HLBW).
6. Identification of high risk group of loss of follow up during NICU stay, and developing interventions to improve accessibility and attendance.

附錄三、受訓綜整報告

Reports on home visit and follow-up program for preterm infants

According to birth notification reports in Taiwan, the proportion of preterm infants is about 10% of all live births, while the proportion of infants with very low birth weight (VLBW) is about 1% of all live births. Although the birth rate in Taiwan is the lowest in the world, the proportion of preterm infants continues to increase. Thanks to health insurance systems and improvements in neonatal care, the infant mortality rate is continuously decreasing, and more very low birth weight infants can now survive. However, these infants and their families face a series of challenges after discharge from hospitals due to the increased risk of developmental issues. Effective intervention and follow-up programs that coordinate different professions are required for VLBW infants to access treatment and early intervention. After reading, digesting all the provided materials, and discussing the topic of classical intervention and follow-up programs for preterm infants in the U.S with Dr. Jason Wang and other scholars, I have learned about the infrastructure and outcomes of different intervention and follow-up programs. During this 4-week study and discussion, I began to reflect on some issues regarding programs for preterm infants currently run by different departments or organizations in Taiwan, which may result in duplication of work. Based on what I have learned at Stanford University; I have drafted some approaches that may be the first step in bridging those gaps.

As a preterm infant discharged from a hospital's NICU setting, it marks the beginning of a series of challenges for both the infants and their families, especially for those with low birth weight. The most profound issue is the neurodevelopment of these infants, which can negatively impact cognitive functions such as IQ and school achievement. Because the first three years of life represent a period of brain plasticity, both timely follow-up and intervention are crucial for future development. My study at Stanford University mainly focused on intervention and follow-up programs in the U.S., their outcome measures, quality care indicators, and some knowledge related to new approaches for improving the neurodevelopment of VLBW infants.

In order to decrease the risk of adverse developmental outcomes and improve neurodevelopment, an effective intervention program with long-term outcome evaluation afterward is important. The Infant Health and Development Program (IHDP) was a classic textbook intervention program for low-birth-weight infants in the U.S., which was conducted at multiple sites across the country, randomized, controlled, and funded by the Robert Wood Johnson Foundation. In this program, the intervention group received intensive measures, including a weekly home visit for the first year and biweekly home visits for the second and third years, center-based early education on weekdays for the second and third years, parent support groups, and regular follow-up. Furthermore, this program evaluated different long-term outcomes for both the intervention and control groups (follow-up only) at different stages (ages

3, 5, 8, and 18). Compared with the control group, low-birth-weight infants receiving intensive care were more likely to have a higher IQ score at 3 years old, but this improvement decreased with increasing age. However, the improvement was sustained in heavier low-birth-weight infants. Other measures such as school achievement and risk behaviors showed the same pattern in heavier low-birth-weight infants. This multi-site, randomized control study with long-term evaluation yielded a high-quality dataset, making it a good candidate for secondary analysis. Here is an example of secondary analysis: the authors of this study hypothesized that the intervention group with a higher IQ at 3 years old would be less likely to need special education at 8 years old compared to the control group; however, the results showed no difference between the intervention and control groups regarding special education usage. Furthermore, a fraction of low-birth-weight children with learning disabilities didn't receive special education, remedial math, remedial reading instruction, or speech therapies, which indicates a large unmet need for special services among children with low birth weight.

Because very low birth weight infants are at high risk for neurodevelopmental, behavioral, and medical sequelae, it's important to have timely follow-up and assess VLBW infants' neurodevelopmental and behavioral status. This requires cooperation between follow-up clinic members and caregivers. The High-Risk Infant Follow-up (HRIF) program is funded by the California State Government and called CCS (California Children's Service). CCS mandates that all CCS-approved NICUs in California should be responsible for identifying and referring eligible infants to the HRIF program. The HRIF program conducts neurodevelopmental assessments, including neurosensory and neurological assessments, and developmental assessments through three clinic visits at 4-8 months, 12-16 months, and 18-36 months. In this study, out of all the discharged VLBW infants, 81% of them received HRIF referrals, and of all HRIF referrals, 76% attended the first HRIF clinics. The authors found that factors with the most significant impact on the first HRIF visit attendance were sociodemographic factors (such as the mother's age), home and environment factors (such as distance from HRIF clinics), and program-based factors (such as HRIF program volume).

When policymakers try to identify the risk factors that influence the measures in the follow-up or whether further outcomes would be affected by the intervention or follow-up measures, linking different datasets is the first step to accomplish this investigation and further improve the quality of care. The Vermont Oxford Network (VON) is a voluntary organization dedicated to improving the quality, safety, and value of care through a coordinated program of data-driven quality improvement, education, and research. This network improves care quality for its members through the collection of structured data items, benchmarking reports, quality improvement collaboratives, pragmatic trials, and observational research. There are some main databases in VON, from the NICU database (including the VLBW database and expanded database) to the follow-up database (for extremely low birth weight infants).

What measures in the follow-up program are both crucial for neurodevelopment with evidence or professional consensus and feasible to record in medical records? Dr. Jason

Wang and his team tried to answer this question in 2006 by reviewing the literature and drafting candidate indicators. They then invited delegates from major associations (such as VON and NICHD) related to this field in the U.S. and used the modified Delphi method, which includes panel discussions, to extract the final indicators with consensus. These 70 indicators comprise five areas: general care, physical health, vision, hearing, speech, and language, developmental and behavioral assessment, and psychosocial issues. The majority of these indicators belong to preventive care, accounting for 83%, which may imply that preventive measures are important for neurodevelopmental follow-up. Surprisingly, just two indicators were supported by level I evidence (randomized control trials), while the majority of these indicators were supported by descriptive studies or expert opinions (level III evidence). With rigorous development processes, I believe that we could use these indicators to measure the quality of follow-up care in Taiwan.

There are two programs in Taiwan that care for and follow up on very low birth weight infants after discharge. In order to alleviate the care burden and pressure on caregivers after discharge, to early detect developmental problems, and to provide timely early intervention, as well as to monitor complications, the Health Promotion Administration launched a nationwide home-based program in 2021. By the end of July 2023, 81 hospitals had implemented this program, covering over 97% of all VLBW infants in Taiwan. Infants weighing over 1,500g with conditions such as comorbidities, medical catheters or devices, or families with low caregiving capability or low socioeconomic status are included in this program. In this program, nurses from home care or NICUs assess the care needs before discharge and provide home visits, virtual visits, and phone visits based on the families' conditions before the babies turn 2 years old corrected age. During this period, nurses would remind and refer VLBW infants to follow-up clinics at 6 months, 12 months, 18 months, and 24 months for further neurodevelopmental examinations, which are covered by national health insurance and included in the premature infant follow-up program. The Premature Infant Follow-up Program is another program run by the Premature Baby Foundation of Taiwan, with 67 hospitals participating. This program covers over 84% of all VLBW infants in Taiwan. Hospitals participating in this program collect NICU-related data and follow up on the health, neurodevelopment, and neurosensory status of all VLBW infants at 6 months, 12 months, and 24 months corrected age, as well as follow up on potential learning problems (e.g., ADHD, comprehension, speaking abilities, developmental coordination disorder, etc.) at 5 years of age. All NICU-related data and follow-up data are collected and registered in the Taiwan Premature Infant Follow-up Network (TPFN) database. A study from the Premature Baby Foundation shows that around 26% of VLBW infants would be lost to follow-up by 24 months corrected age.

When reading these research articles and discussing with professors and scholars, I realized that the first step for quality improvement is high-quality, reliable data that reflects outcomes. Useful information can be generated from high-quality data. Finally, actions that support frontline perinatal care providers in designing and conducting their work could lead to quality improvement. All these processes would be possible only when high-quality, reliable data exist. When I inventoried different preterm infant-related programs that currently run by different departments or organizations in Taiwan, I found that these programs may require integration, both in services and databases. So I used the framework of the CPQCC/CMQCC data center and listed all candidate programs in Taiwan to find possible ways to integrate. I hope that through the integration of these programs, we could decrease the duplication of workload for frontline care providers and improve the quality of care.

I also listed some possible strategies that may improve care quality based on what I learned during this 4-week study. The first strategy is establishing a nationwide quality improvement collaborative, which could recruit the Taiwan Society of Neonatology (Taiwan Neonatal Network), the Taiwan Pediatric Association, the Premature Baby Foundation of Taiwan, public health professionals, and government officials, among others, to join as members. The objectives of this collaborative include exchanging data from different programs, identifying quality-of-care indicators, measuring outcomes (especially for follow-up), and improving the quality of care through peer comparison, benchmarking, and performance improvement activities. By doing this, I believe it's possible to continuously improve the quality of care for preterm infants.

The second strategy is to encourage parents' engagement (talk) during NICU stays. Evidence highly suggests that parent talk in the NICU 4 weeks and 8 weeks prior to an infant's due date has a powerful impact on subsequent infant language and cognitive development.

The third strategy is changing the follow-up strategy for motor impairment. For example, the assessment for cerebral palsy is common in current follow-up programs, both in the U.S. and Taiwan. However, more and more studies show that developmental coordination disorder (DCD) is becoming more prevalent, and children with DCD may encounter academic challenges, behavior problems, or decreased participation in sports in school. Therefore, it's important to assess for developmental coordination disorder before school age. So, maybe it's time for us to rethink the items in follow-up programs.

Regarding the future work of the home visit project for very low birth infants in Taiwan, I noticed a lack of intensive early education in the module of the program, compared with the IHDP program. Therefore, I would start to investigate the possibilities of incorporating early education programs into the home visit project by cooperating with social welfare department officials, who manage early education programs in Taiwan.