

RGC Ref. No.: UGC/FDS15/H04/21 (please insert ref. above)

**RESEARCH GRANTS COUNCIL
COMPETITIVE RESEARCH FUNDING SCHEMES FOR
THE LOCAL SELF-FINANCING DEGREE SECTOR**

FACULTY DEVELOPMENT SCHEME (FDS)

Completion Report
(for completed projects only)

<p><u>Submission Deadlines:</u></p> <ol style="list-style-type: none"> 1. Auditor's report with unspent balance, if any: within <u>six</u> months of the approved project completion date. 2. Completion report: within <u>12</u> months of the approved project completion date.
--

Part A: The Project and Investigator(s)

1. Project Title

How do ethnic minorities cope with cancer in Hong Kong? The role of public health
services, social network and religion

2. Investigator(s) and Academic Department(s) / Unit(s) Involved

Research Team	Name / Post	Unit / Department / Institution
Principal Investigator	Dr. LAU Flora Pui-yan Associate Professor	Department of Sociology, Hong Kong Shue Yan University
Co-Investigator(s)	N/A	N/A
Others	N/A	N/A

3. Project Duration

	Original	Revised	Date of RGC / Institution Approval (must be quoted)
Project Start Date	1 st January 2022	N/A	N/A
Project Completion Date	31 st December 2023	N/A	N/A
Duration (in month)	24 months	N/A	N/A
Deadline for Submission of Completion Report	31 st December 2024	N/A	N/A

- 4.4 Please attach photo(s) of acknowledgement of RGC-funded facilities / equipment.
N/A

Part B: The Final Report

5. Project Objectives

5.1 Objectives as per original application

1. To describe the difficulties and needs of ethnic minority cancer patients and their caregivers in Hong Kong
2. To evaluate the effectiveness of local healthcare services, in particular the palliative care, for ethnic minority cancer patients in Hong Kong based on the experiences and comments of ethnic minorities and medical professionals
3. To analyse the roles of informal networks and religion and faith in cancer treatment and the ways through which ethnic minorities mobilize resources through these networks
4. To recommend culturally competent healthcare measures for cancer patients and their caregivers so as to bring the betterment of this population

5.2 Revised objectives

Date of approval from the RGC: N/A

Reasons for the change: N/A

5.3 Realisation of the objectives

(Maximum 1 page; please state how and to what extent the project objectives have been achieved; give reasons for under-achievements and outline attempts to overcome problems, if any)

How to achieve the objectives

The PI completed 38 in-depth interviews with ethnic minority cancer patients/survivors (21), caregivers (4) and healthcare practitioners (13) between April 2022 and October 2023. The ethnic minority cancer patients/survivors and caregivers were of Indian, Filipino, Indonesian or Nepalese origin. While most of patients/ survivors were diagnosed of breast cancer (15), the others were of colon (2), cervical (2), liver cancer (1) and lymphoma (1) cancer. Seventeen of the interviewees were female and four of them were male. These cancer patients and survivors were aged between 29 and 59 and most of them were in their forties and fifties. The thirteen healthcare practitioners include doctors serving in public hospitals in Hong Kong (4), nurses (2), social workers of mainstream NGOs (4) and grassroots NGO leaders (3) and were ethnically Hong Kong Chinese or of Nepalese, Indian, Indonesian or Filipino origin. These interviews helped to recognise the challenges of different professionals encountered when interacting with

ethnic minority cancer patients and their caregivers and the ways they handled these challenges. Lastly, a comprehensive literature review on the difficulties of ethnic minority patients, the insufficiencies of local public healthcare services and the possibilities and measures for culturally competent healthcare services were completed.

The extent to which each project objective is achieved

Upon the completion of the project, objectives 1, 2 and 4 are fully achieved while objective 3 is partially achieved. With regard to objective 1, the ethnic minority cancer patients and caregivers extensively shared with the PI their worries and frustration during the cancer healing process. They worried about the possibility of being unemployed, the lack of financial resources, the worsening of physical health, the risk of death and the wellbeing of their family members especially for those who have young children and those with family members overseas. Most of them told the PI they need instrumental and emotional support as well as better healthcare services.

Regarding objective 2, while some cancer patients expressed discontent with the hectic medical services and the language barriers they encountered in public hospitals, a substantial number of them greatly appreciated the public healthcare services. They were particularly grateful of the opportunity, be they permanent citizens or migrant workers, to receive very professional medication in Hong Kong. The medical professional respondents, i.e. doctor and nurse admitted that the manpower is insufficient in the public health sector which in turn, reduced their time spent to effectively communicate with these patients and their caregivers. They openly shared their views and made essential recommendations. Please refer to Part B 6.1 for details.

Regarding objective 4, respondents of all backgrounds agreed with the need to enhance culturally competent healthcare measures such as the delivery of more effective interpretation services and an increase in resources (e.g. more choices of Southeast Asian food) for the daily needs of ethnic minorities. In addition, measures such as an increase in cultural competence outreach programmes at schools or community organizations, and more importantly, the building up trust and strong foundation in doctor-patient relationship is encouraged.

As to objective 3, the role of informal social network in cancer management was very clearly articulated by respondents. This network is facilitated through social media, Whatsapp groups and grassroot NGO mobilization. Nevertheless, the role of religion was emphasized by in a general manner. For instance, respondents of Muslim, Catholics and Christian backgrounds highlighted the essentiality to pray and to trust God but without much elaboration. This might be due to the fact that the PI is non-religious and thus, needs to be more sensitive to develop an in-depth conversation on religious matters with the respondents. Having said that, the role of religion in cancer healing can be further analysed in research ahead. Please refer to Section 6.2 for elaboration.

5.4 Summary of objectives addressed to date

Objectives (as per 5.1/5.2 above)	Addressed (please tick)	Percentage Achieved (please estimate)
1. To describe the difficulties and needs of ethnic minority cancer patients and their caregivers in Hong Kong	✓	100%

2. To evaluate the effectiveness of local healthcare services, in particular the palliative care, for ethnic minority cancer patients in Hong Kong based on the experiences and comments of ethnic minorities and medical professionals	✓	100%
3. To analyse the roles of informal networks and religion and faith in cancer treatment and the ways through which ethnic minorities mobilize resources through these networks	✓	90%
4. To recommend culturally competent healthcare measures for cancer patients and their caregivers so as to bring the betterment of this population	✓	100%

6. Research Outcome

6.1 Major findings and research outcome

First, drawing on Woolcock's framework of social capital (1998), this research demonstrates that the cancer coping process can be substantially improved with bonding, bridging and linking social capital, which can be facilitated by community leaders. In particular, grassroots NGOs established by community leaders are of paramount importance in providing patients with more sustainable resources owing to their competence in engaging these patients and to identify relevant resources for them. This finding gives rise to a manuscript in a referred journal (under review), two conference presentations in May 2024 and Dec 2023 and one panelist discussion in a seminar organized by an ethnic minority healthcare NGO. For details, please refer to Part C8-9 and Appendix 1, 3, 4 and 10 respectively. Please also note that Appendix 1 (i.e. the manuscript) was developed from Appendix 4 (i.e. a conference presentation).

Second, the findings show that issues of cultural competence are alert in Hong Kong's healthcare system and NGOs. Doctors made precise suggestions on how to improve the service: first, to group ethnic minority cases together so that the doctors will see less patients overall but they will all be ethnic minority patients. A translator will be reserved and be there the whole time. Second, there shall be more policy initiatives from the middle management of the public healthcare sector rather than just listening to the senior management. Third, hospitals shall introduce patients to each other when they are waiting for their appointment if they speak the same language and suggest diet/exercise classes for groups. Fourth, the Hospital Authority is advised to hire more ethnic minority doctors. Fifth, there is a need to do more as a community for the minority population e.g. community clubs can reach out to hospitals/clinics for more information or actively as for a session on a specific issue. Moreover, ethnic minority cancer patients are very much alive to these issues and understand that they must navigate their way through it in order to obtain the treatment they need and answers to their medical questions. The discussion on cultural competence gives rise to a manuscript in a referred journal (in preparation) and one conference presentations in Sept 2023. For details, please refer to Part C8-9 and Appendix 2 and 5. Please also note that Appendix 2 (i.e. the manuscript) was developed from Appendix 5 (i.e. a conference presentation)

Third, social media and other digital device is essential in the healing process. Ethnic minority cancer patients relied heavily on online support ranging from daily conversation, an exchange of information, the consumption and production of YouTube as well as the consultation with online psychic and spiritual healers. These support measures have helped them to overcome the jinx in various ways and was especially the case during the COVID period. This research finding gives rise to two conference presentations in Jun 2023 and Dec 2022. For details, please refer to Part C9 and Appendix 7 and 9 for further information.

Fourth, methodologically, this research offers new insights into researching the hidden population especially on the aspect of ethical consideration. The passing away of two respondents several months after the interview alerted the PI her relation with the respondents. In a conference presentation at Oxford, the PI discussed whether the relationship with the respondents will end after the fieldwork and if so, whether the researcher would be guilty of taking advantage of this group of population. Please refer to Part C9 and Appendix 6.

Lastly, over the research period, the PI had gathered knowledge via in-depth interviews and literature review regarding the practical needs of ethnic minority cancer patients in Hong Kong. To name some, these needs include the attainment of cancer healing information and monetary and emotional support. To address their needs, the PI gave a talk on where ethnic minority patients can seek help. The PI also assisted the publication of an information booklet for migrant workers. Please refer to Part C9 and C10 respectively (i.e. Appendix 8 and 11).

6.2 Potential for further development of the research and the proposed course of action

The research can potentially lead to the following areas of development. First, based on the existing findings, the PI will further explore the mechanisms through which spirituality, as opposed to Western medicine, transforms the sense of self of a patient and enhances cancer management and health outcomes.

Second, a significant proportion of breast and cervical cancer interviewees worried about their intimate relationship with their spouse due to the impairment of breast and the reproductive system – the fear of loss in femininity from a critical gender perspective. Further research on how women cancer survivors cope with different domains of life (i.e. couple relationship, sexual difficulties, negative perception of the future and even barriers in work) in post-cancer period can be well-developed. Potential questions include: 1) how do breast and cervical cancer survivors perceive their body, conjugal relationship and other domains of life in post-cancer period? and 2) what other coping strategies can be developed out of their previous experiences and existing resources? The above issues can be central to the PI's next FDS application.

Third, most of the ethnic minority cancer patients heartfully share their experiences of cancer coping. As quite a number of them gave their narrative from the perspective of a doubly marginal group of the society (i.e. as ethnic minorities and as patients of critical illness), it certainly provides an alternative angle to understand life coping and resilience. The Emerald Publishing has contacted the PI in late November for the possibility of publishing a book which comprises a collection of stories on life struggle and resilience of ethnic minorities. The PI will press on with this project.

Lastly, one of the key research findings shows that ethnic minority cancer patients rely heavily on social media and online communication. In light of this, the PI can develop further research on the digital divide of ethnic minority population and its impacts on healthcare prevention and management in Hong Kong. Potential questions include: 1) in what ways, if there is any, are ethnic minorities benefitted from e-health promotion initiated by the government/ NGOs in HK?; 2) what are the barriers for them to get access to e-health information? and 3) in general, how can health literacy be promoted to the ethnic minority community?

7. Layman's Summary

This research aims to explore the difficulties and coping strategies of ethnic minority cancer patients in Hong Kong. Key questions include: what are the difficulties and needs of ethnic minority cancer patients and their caregivers? To what extent is the local healthcare services effective and adequate for these patients? What are the roles of informal social network, religion and online communities in the cancer healing process? This research gathers firsthand information from 21 ethnically Southeast Asian cancer patients and survivors, 4 caregivers and 13 healthcare professionals and NGOs practitioners in Hong Kong.

This information serves the following purposes. First, it will allow the public to identify existing issues in cancer-related healthcare and support services for ethnic minorities and to recommend culturally competent measures for patients, caregivers and healthcare professionals. Second, while it addresses the inadequacies of mainstream NGOs in supporting cancer management of the ethnic minority population, it assures the achievement of grassroots NGOs in helping out this group of people. Third, through booklet and online media, it provides practical information to people of ethnic minority on how and where to seek help in Hong Kong if diagnoses of cancer – an information which is rarely systematically organized and circulated.

Part C: Research Output**8. Peer-Reviewed Journal Publication(s) Arising Directly From This Research Project**

(Please attach a copy of the publication and/or the letter of acceptance if not yet submitted in the previous progress report(s). All listed publications must acknowledge RGC's funding support by quoting the specific grant reference.)

The Latest Status of Publications				Author(s) (denote the corresponding author with an asterisk*)	Title and Journal / Book (with the volume, pages and other necessary publishing details specified)	Submitted to RGC (indicate the year ending of the relevant progress report)	Attached to this Report (Yes or No)	Acknowledged the Support of RGC (Yes or No)	Accessible from the Institutional Repository (Yes or No)
Year of Publication	Year of Acceptance (For paper accepted but not yet published)	Under Review	Under Preparation (optional)						
N/A	N/A	Yes	--	Pui Yan Flora LAU	<u>Title:</u> Mobilising healthcare resources through social capital: Cancer management for ethnic minority patients in Hong Kong <u>Journal:</u> <i>Sociology of Health and Illness</i>	No	Yes (Refer to Appendix 1)	Yes	No
N/A	N/A	N/A	Yes	Pui Yan Flora LAU	<u>Title:</u> Towards a culturally competent healthcare environment for ethnic minority cancer patients in Hong Kong: the perspective of clients and NGOs <u>Journal:</u> <i>Health & Social Care in the Community</i>	No	Yes (Refer to Appendix 2)	Yes	No

9. Recognized International Conference(s) In Which Paper(s) Related To This Research Project Was / Were Delivered

(Please attach a copy of each conference abstract)

Month / Year / Place	Title	Conference Name	Submitted to RGC <i>(indicate the year ending of the relevant progress report)</i>	Attached to this Report <i>(Yes or No)</i>	Acknowledged the Support of RGC <i>(Yes or No)</i>	Accessible from the Institutional Repository <i>(Yes or No)</i>
May/ 2024/ Hong Kong	Handling mental health issues of migrant domestic workers in Hong Kong: The role of NGO and community life	Migrant Worker Lives Matter Symposium (By invitation, organized by Department of English and Communication at PolyU in collaboration with Pathfinders and Mission for Migrant Workers)	No	Yes (Refer to Appendix 3)	Yes (in ppt)	Yes
Dec/ 2023/ Hong Kong	Mobilizing healthcare resources through social capital: the case of ethnic minority cancer patients in Hong Kong	The 24 th Annual Conference of the Hong Kong Sociological Association	No	Yes (Refer to Appendix 4)	Yes (in ppt)	Yes
Sept/ 2023/ Sussex, UK (online)	A critical evaluation of cultural competence in medical sector: perspectives of ethnic minority cancer patients and local healthcare professionals in Hong Kong	British Sociological Association Medical Sociology Conference 2023	No	Yes (Refer to Appendix 5)	Yes (in ppt)	Yes
Aug/ 2023/ Oxford, UK	Researching asylum seekers and ethnic minority cancer patients in Hong Kong: some methodological and ethical concerns	Hard-to-Reach: Applied Research Methods with Hidden, Marginal, and Excluded Populations (Organized by Centre for Experimental Social Science, Nuffield College, in partnership with the UNICEF Regional Office for East Asia and Pacific)	No	Yes (Refer to Appendix 6)	Yes (in ppt)	Yes

June/ 2023/ Melbourne, Australia	Healing through social media: Experiences of ethnic minority cancer patients and survivors in Hong Kong	RC16 Sociology of Health, XX International Sociological Association, World Congress of Sociology	Yes	Yes (Refer to Appendix 7)	Yes (in ppt)	Yes
Feb/ 2023/ Hong Kong	Breast and cervical cancer: places to seek help in Hong Kong	Social Justice for Migrant Workers on 26 th February 2023	No	Yes (Refer to Appendix 8)	Yes (in ppt)	Yes
Dec/ 2022/ Hong Kong	Mobilizing social capital in times of social distancing: digital communication among ethnic minority cancer patients in Hong Kong	The 23 rd Annual Conference of the Hong Kong Sociological Association	Yes	Yes (Refer to Appendix 9)	Yes (in ppt)	Yes
Nov/ 2022/ Hong Kong	The Essence of Building Resilience in the Multicultural Community (served as a Panelist of the discussion)	Health In Action Ethnic Minorities Multicultural Assembly 2022	Yes	Yes (Refer to Appendix 10)	Yes (orally during the panel discussion)	No

10. Whether Research Experience And New Knowledge Has Been Transferred / Has Contributed To Teaching And Learning
(Please elaborate)

While the PI was kicking off the research fieldwork on her own in April 2022, she was able to be in touch with different stakeholders including ethnic minority community leaders, members of grassroots/mainstream NGOs, medical professionals and of course, ethnic minority cancer patients. The following case demonstrates how her research experience has been transferred and contributed to enhance people's health literacy in the community:

1. The PI was invited to give a talk entitled 'Breast and Cervical Cancer: Places to seek help in Hong Kong' on 26th February 2023 at the Hong Kong Bayanihan Kennedy Town Centre. The talk was reported by HONG KONG NEWS on 28th February 2023: https://fb.watch/i_BtSFIKa6/
2. Two months after the talk, the PI reviewed the draft of and gave advice to a booklet, *Breast and Cervical Cancer: Things You Should Know*, produced by Social Justice for Migrant Workers and supported by Translate for Her, 2023 (please refer to Appendix 11). 2000 hardcopies were published and distributed to migrant workers in Hong Kong. The softcopy was once uploaded on the Philippine Consulate official Facebook page: <https://www.facebook.com/photo.php?fbid=563911462597245&set=pb.100069351890104.-2207520000&type=3>
3. The booklet, together with a presentation (refer to Appendix 8) was reported on TVB Kabayan, a Filipino-based TVB channel in Hong Kong on 7th May 2023: https://www.youtube.com/watch?app=desktop&v=nr_sUMq2Vc

The transferal of knowledge as indicated above has indeed benefitted the ethnic minority communities via the talk, publication of the booklet and online media.

11. Student(s) Trained

(Please attach a copy of the title page of the thesis)

Name	Degree Registered for	Date of Registration	Date of Thesis Submission / Graduation
N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A

12. Other Impact

(e.g. award of patents or prizes, collaboration with other research institutions, technology transfer, teaching enhancement, etc.)

1. As a result of being heavily engaged in this research project (which is unique in both academic and non-academic world), the PI was gradually able to establish herself professionally. The current research in caregiving for the desperate and hidden population has allowed her to contribute to the academic sector by being an External Examiner for a PhD candidate at Department of Sociology and Social Policy, Lingnan University in December 2023. The thesis title is “There is nothing I can do: lived experiences, perceptions, and caregiving trajectories of family caregivers of youth with substance use disorders (SUDs) in Zambia”, a topic that is highly relevant to the PI’s project.
2. The PI was invited by SAGE Research Method, a digital research library in December 2024 to contribute to a new educational collection ‘*Sage Research Methods: Hard-to-Reach & Sensitive Research*’. The collection will focus on 1) research with groups that are considered ‘hard to reach’ or ‘difficult to access’ and, 2) research concerned with sensitive topics. It will be published in 2026.
3. As the PI has connected to various ethnic minority organizations over the past three years, further collaboration can be emerged out of these connections and thereby, making impacts to the EM and local healthcare communities. For example, in late 2022, a grassroot NGO, Health in Action (HIA) consulted the PI a case in which an ethnically Indian Hong Kong citizen has problems with relocation to Hong Kong for advanced medication. By giving advice and sharing with HIA with regard to the local healthcare and immigration policies, the PI contributes to the EM community with her professional knowledge and to the local healthcare sector with clarifying the policies to those who are confused.
4. The PI was invited by the Filipino Migrants Support for Cancer Society on 12th November 2023 to take part in a symposium entitled ‘Cancer Awareness Symposium for Migrants: You are not alone’. She was invited to deliver an ‘Inspirational message’ to cheer up the attendees. More than 100 Filipino migrant workers attended the event.

13. Statistics on Research Outputs

	Peer-reviewed Journal Publications	Conference Papers	Scholarly Books, Monographs and Chapters	Patents Awarded	Other Research Outputs (please specify)	
No. of outputs arising directly from this research project	2 (1 under review and 1 in preparation)	8	N/A (1 in liaison)	N/A	Type	No.
					Information booklet	2,000 copies

14. Public Access Of Completion Report

(Please specify the information, if any, that cannot be provided for public access and give the reasons.)

Information that Cannot Be Provided for Public Access	Reasons
N/A	N/A