

# STEM CELL TOURISM AND THE POLITICAL ECONOMY OF HOPE

ALAN PETERSEN, MEGAN MUNSIE,  
CLAIRE TANNER, CASIMIR MACGREGOR,  
JANE BROPHY



Health,  
Technology &  
Society



# Health, Technology and Society

## **Series Editors**

Andrew Webster  
Department of Sociology  
University of York  
York, UK

Sally Wyatt  
Royal Netherlands Academy of Arts  
Amsterdam, The Netherlands

Medicine, health care, and the wider social meaning and management of health are undergoing major changes. In part this reflects developments in science and technology, which enable new forms of diagnosis, treatment and delivery of health care. It also reflects changes in the locus of care and the social management of health. Locating technical developments in wider socio-economic and political processes, each book in the series discusses and critiques recent developments in health technologies in specific areas, drawing on a range of analyses provided by the social sciences. Some have a more theoretical, some a more applied focus but all draw on recent research by the authors. The series also looks toward the medium term in anticipating the likely configurations of health in advanced industrial society and does so comparatively, through exploring the globalization and internationalization of health.

More information about this series at  
<http://www.springer.com/series/14875>

Alan Petersen • Megan Munsie • Claire Tanner •  
Casimir MacGregor • Jane Brophy

# Stem Cell Tourism and the Political Economy of Hope

palgrave  
macmillan

Alan Petersen  
Sociology  
School of Social Sciences  
Monash University  
Clayton, VIC, Australia

Megan Munsie  
Centre for Stem Cell Systems  
Department of Anatomy and Neuroscience  
University of Melbourne  
Parkville, VIC, Australia

Claire Tanner  
Centre for Stem Cell Systems  
Department of Anatomy and Neuroscience  
University of Melbourne  
Parkville, VIC, Australia

Casimir MacGregor  
Sociology  
School of Social Sciences  
Monash University  
Clayton, VIC, Australia

Jane Brophy  
Sociology  
School of Social Sciences  
Monash University  
Clayton, VIC, Australia

Health, Technology and Society  
ISBN 978-1-137-47042-3      ISBN 978-1-137-47043-0 (eBook)  
DOI 10.1057/978-1-137-47043-0

Library of Congress Control Number: 2016956384

© The Editor(s) (if applicable) and The Author(s) 2017

The author(s) has/have asserted their right(s) to be identified as the author(s) of this work in accordance with the Copyright, Designs and Patents Act 1988.

This work is subject to copyright. All rights are solely and exclusively licensed by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made.

Cover image: Fotolia.com

Printed on acid-free paper

This Palgrave Macmillan imprint is published by Springer Nature  
The registered company is Macmillan Publishers Ltd. London  
The registered company address is: The Campus, 4 Crinan Street, London, N1 9XW, United Kingdom

“Accessibly written and vividly illustrated with rich empirical examples, the book reframes our understanding of medical tourism and problematizes academic and policy responses to this growing phenomenon.”

–Ruth Holliday, Professor in the School of Sociology  
and Social Policy, University of Leeds, UK

“...This terrific book is more than just an overview of the facts, it provides a unique and tremendously informed perspective on the drivers of stem cell tourism and how the policy debates can be reframed in a constructive manner.”

–Timothy Caulfield, Faculty of Law and School of  
Public Health, University of Alberta

“Hope has been the constitutive element of stem cell research and therapy. Every year thousands of patients travel overseas to obtain stem cell therapy for a variety of conditions... this book provides an analytically suave and empirically rigorous account of the transnational landscape of stem cell therapies. Alan Petersen and his co-authors force us to rethink the accepted understanding of stem cell tourism. A must read!”

–Amit Prasad, Ph.D., Associate Professor of Sociology,  
University of Missouri-Columbia

“Healthcare markets are... departing from standard biomedical orthodoxies [and] Stem cell markets have crafted niches across radically divergent regulatory jurisdictions. This book makes a remarkable contribution to our understanding of these forces, helping us to understand dynamics that are actively reshaping the global biomedical landscape.”

–Professor Nik Brown, Department of  
Sociology, University of York

## Series Editors' Preface

Medicine, healthcare, and the wider social meaning and management of health are undergoing major changes. In part, this reflects developments in science and technology, which enable new forms of diagnosis, treatment, and delivery of healthcare. It also reflects changes in the locus of care and burden of responsibility for health. Today, genetics, informatics, imaging, and integrative technologies, such as nanotechnology, are redefining our understanding of the body, health, and disease; at the same time, health is no longer simply the domain of conventional medicine, nor of the clinic. The 'birth of the clinic' heralded the process through which health and illness became increasingly subject to the surveillance of medicine. Although such surveillance is more complex, sophisticated, and precise as seen in the search for 'predictive medicine', it is also more provisional, uncertain, and risk laden.

At the same time, the social management of health itself is losing its anchorage in collective social relations and shared knowledge and practice, whether at the level of the local community or through state-funded socialised medicine. This individualisation of health is both culturally driven and state sponsored, as the promotion of 'self-care' demonstrates. The very technologies that redefine health are also the means through which this individualisation can occur—through 'e-health', diagnostic tests, and the commodification of restorative tissue, such as stem cells, cloned embryos, and so on.



This Series explores these processes within and *beyond* the conventional domain of 'the clinic', and asks whether they amount to a qualitative shift in the social ordering and value of medicine and health. Locating technical developments in wider socioeconomic and political processes, each text discusses and critiques recent developments within health technologies in specific areas, drawing on a range of analyses provided by the social sciences and especially from those working in the field of science and technology studies.

The Series has already explored many of these issues, presenting novel, critical, and deeply informed research undertaken by their authors. In doing so, the books have shown how the boundaries between the three core dimensions that underpin the whole Series—health, technology, and society—are changing in fundamental ways. This latest addition to the Series examines an area which has attracted considerable debate and controversy, the arrival over recent years of what has become known as 'stem cell tourism'.

This book explores and challenges many of the assumptions on which the term 'stem cell tourism' is based, offering a nuanced and insightful analysis of how and why people seek treatment for very debilitating or terminal illnesses and disease, either in their own country or elsewhere. Based on research by the authors conducted over a number of years, the analysis is framed around the concepts of 'the political economy of hope' and the 'treatment journey', providing a detailed, qualitative exploration of patients' highly reflexive understandings of their conditions and what stem cells might offer. The authors discuss how stem cell treatment is often seen as a treatment of last resort, but within a complex and increasingly commercialised market for healthcare and its delivery. They point to the differences between countries in regard to public and private provision, considerable unevenness in terms of access to care, and, crucially, key differences in national regulatory systems relating to stem cell therapies.

The search for stem cell therapies to treat or even cure disease is part of a much wider set of developments in the area of regenerative medicine (RM). There has been some social science analysis of this field, not least through two earlier contributions to the Series (Gottweis et al. 2009; Webster 2013). RM is championed as a potential source of curative treatments for a variety of illnesses, and as a generator of economic wealth

and prosperity. Alongside this optimism, however, is a sense of concern that the translation of basic science into useful RM therapies will be laboriously slow due to a range of challenges relating to live-tissue handling and manufacturing, regulation, reimbursement, and commissioning, and to actual adoption in the clinic. This in part explains and provides the wider context through which we can understand individuals and their families trying, through their own efforts, to access therapy where they can. There is a pressing need to have an informed, social science analysis of this phenomenon that not only makes an important academic contribution but also offers insight and guidance for policymakers, and indeed patients themselves.

The authors have extensive and impressive expertise in this field and have brought this together in an exceptionally well-organised way, based on a strongly integrated conceptual framework. As Series' Editors we are delighted to mark our latest publication with a book which will attract international interest from social science scholars working across a number of disciplines. It will also be of great interest to researchers and practitioners in the stem cell field, and those who are considering the prospect of searching for treatment in the world of stem cells.

Andrew Webster and Sally Wyatt

# Acknowledgements

This book was only possible through the generosity of the many individuals who so openly shared their stories and insights with us. We thank you. We would especially like to acknowledge the patients and carers who so willingly reflected on their hopes, frustrations, and experiences—which at times may have been confronting as they revisited topics that perhaps they had not thought about for some time or were painful to recall. To the many professionals, in Australia as well as in Germany and China, who shared their views about stem cell science and its clinical application, you have provided us with a unique insight into the challenge of managing hopes and expectations. We would also like to thank the organisations that provided assistance and advice in recruiting participants to this study, including the Australia–New Zealand Spinal Cord Injury Network, Cerebral Palsy Support Network, Cerebral Palsy Alliance, Motor Neurone Disease Australia and affiliated state chapters, MS Australia, Alzheimer’s Australia Research Ltd., Parkinson’s Victoria, Murdoch Children’s Research Institute, and the Friedreich Ataxia Research Association.

We wish to thank the Australian Research Council for funding the research upon which this book is based, namely ‘High Hopes, High Risk?: A Sociological Study of Stem Cell Tourism’ (DP120100921). We would also like to acknowledge the funding provided by the then Australian government Department of Innovation, Industry, Science and

Research, under the National Enabling Technologies Strategy for the pilot project completed in 2010, and our colleagues Dr. Kate Seear from Monash University and Rebecca Skinner from the then Australian Stem Cell Centre, who were invaluable members of the original research team.

While all of us worked together closely in developing the outline, themes, and content for the book, we each took primary responsibility for different chapters—Alan for Chaps. 1 and 8 and jointly Chap. 2 with Claire; Megan for Chap. 3 and jointly Chap. 7 with Casimir; Claire, Casimir, and Jane led Chaps. 4, 5, and 6, respectively. Ethics approval for all interviews was obtained from Monash University’s Human Research Ethics Committee. Some of the material used in the book features in other publications by this group or has been presented at various forums. Chapter 2 draws partly on material prepared for the workshop ‘International Medical Travel and the Politics of Transnational Mobility in Asia’, organised by the Asia Research Institute in August 2015. Chapter 3 builds upon our paper in *Health* (Petersen et al. 2015) by providing a more detailed description of the role of stakeholders, their perspectives, and the factors that have contributed to the heightened expectations in stem cell science. Chapter 4 builds on and extends our earlier work on patient experience first published in the *Sociology of Health and Illness* (Petersen et al. 2014). Chapter 5 was only possible through the support and hospitality shown to Casimir during his time in Germany. We would like to specifically acknowledge Jovan Maud, Ira Herrmann, Martin Heyer, Rita and Rainer Sobetzki, and Professor Michael Fuchs as well as thank Kate Doherty at EuroStemCell for her ongoing interest in our German research. Chapter 6 draws on research undertaken towards Jane Brophy’s PhD candidature, and for this, we wish to acknowledge the generous donor of the Monash University *Science in Society* PhD scholarship, who wishes to remain anonymous, as well as the Monash University Faculty of Arts and the School of Social Sciences for providing additional funding. We would also like to thank Dr Lai Lili and the Institute of Medical Humanities at Peking University for their support during Jane’s time in China.

Alan Petersen is grateful for the feedback gained from an invited presentation to a workshop on stem cell therapies organised by the US National Academy of Sciences, International Society for Stem Cell Research, and

the Institute of Medicine in Washington, DC, in November 2013. He would like to thank the Brocher Foundation and staff who supported his residence in November 2014, which provided the opportunity to develop and share his ideas. While he was at Brocher, Aditya Bharadwaj generously invited him to his conference 'Intersections: social science and bioscience perspectives on stem cell technologies', which enabled him to meet some key individuals working in the field. The World Health Organization also invited him to present findings from his work, which provided an invaluable opportunity to share ideas with those who are grappling with regulatory issues, and he would like to express his thanks to them.

The team as a whole presented the main findings at a stakeholder workshop held at the University of Melbourne in September 2015, and we wish to thank attendees for their participation and feedback and Stem Cells Australia for generously hosting the event. We thank Palgrave Macmillan, and Dominic Walker and Stephanie Carey in particular, for the support offered at all stages of the book's production and for kindly accommodating our requests for extensions. Finally, we wish to express our gratitude to our families and our institutions for their support.

The views and interpretations expressed in the book are the authors' and do not necessarily represent the views of Monash University, Stem Cells Australia, the University of Melbourne, or the funding bodies.

## References

- Petersen, A., Seear, K., & Munsie, M. (2014). Therapeutic journeys: The hopeful travails of stem cell tourists. *Sociology of Health and Illness*, 36(5), 670–685.
- Petersen, A., Tanner, C., & Munsie, M. (2015). Between hope and evidence: How community advisors demarcate the boundary between legitimate and illegitimate stem cell treatments. *Health*, 19(2), 188–206.

# Contents

<b>1</b>	<b>Stem Cell Tourism in Context</b>	<b>1</b>
<b>2</b>	<b>'Choice', Hope, and Stem Cell Treatments</b>	<b>31</b>
<b>3</b>	<b>Managing Hope</b>	<b>59</b>
<b>4</b>	<b>Hopeful Journeys of Stem Cell Tourists</b>	<b>83</b>
<b>5</b>	<b>Exploiting Stem Cell Hopes in Germany</b>	<b>101</b>
<b>6</b>	<b>Selling Hope in China</b>	<b>121</b>
<b>7</b>	<b>Hope 'at Home': Stem Cell Treatments in Australia</b>	<b>155</b>
<b>8</b>	<b>Re-framing 'Stem Cell Tourism'</b>	<b>185</b>
	<b>Appendix</b>	<b>203</b>
	<b>Index</b>	<b>211</b>
		<b>xv</b>

# List of Tables

Table 1	Overview of interviewees who had travelled for stem cell treatments	204
Table 2	Overview of interviewees who had considered travelling for stem cell treatments but had not done so at the time of interview	207
Table 3	Overview of online educational resources designed to assist those wanting to find out more about how stem cells are being used in medical research and in the clinic	208
Table 4	Overview of TGA's 2015 proposed options for the regulation of autologous cells in Australia	209

# 1

## Stem Cell Tourism in Context

In Australia, in recent years, there have been a number of news reports of patients and carers travelling overseas for stem cell treatments (e.g. Donaghey 2013; MacLennan 2014). Their journeys are part of a wider international trend, commonly referred to as stem cell tourism, whereby patients and carers of patients travel across geographical borders and jurisdictions to receive treatments that are experimental or clinically unproven, and hence, may not be available to them where they live. The stories which the articles tell are framed within a now-familiar narrative—desperate patients full of hope investing in treatments that promise much, and scientists and doctors voicing frustrations about entrepreneurial ‘charlatans’ or ‘cowboys’ operating at the margins of medicine and exploiting ‘regulatory loopholes’ to sell ‘snake oil’. Why, authorities ask, do patients and carers embark on such treatments that are unlikely to provide benefit, are expensive, and potentially inflict great harm?

This book explores the stem cell tourism phenomenon in all its complexity, so as to cast light on the various sociocultural factors that shape patients’ and carers’ decisions to embark on journeys to pursue such treat-



ments as well as the nature of current responses to this issue. We wish to go beyond simplistic portrayals of ‘the problem’, how ‘it’ arises, who is to ‘blame’, and what should be ‘regulated’, which characterises much of the academic and media portrayal of stem cell tourism, to uncover the dynamics of a rapidly evolving treatment market. We question the current ways of understanding the stem cell tourism phenomenon including some underlying premises shaping the terms of recent discussion and the language used to frame stories such as those above, and ask, what is left out of the frame? And, how may ‘stem cell tourism’ be re-framed so as to offer a better appreciation of why individuals pursue these treatments and whether authorities’ concerns are justified and their responses are appropriate and proportionate to the purported risks or concern over lack of demonstrated benefit.

An analysis of the stem cell tourism phenomenon, we believe, can reveal much about how new markets based on emerging technologies arise, operate, and are sustained in the context of contemporary health-care. This is a context where national and jurisdictional borders matter much less than they did in the past and where citizens have become ‘consumers’ called upon to exercise ‘informed choice’ in decisions about health, risk, and care. We ask, what does ‘informed choice’ mean in this context, especially when individuals are experiencing life-threatening or life-limiting conditions and where conventional treatment options are few or non-existing? And, who are the ‘choice architects’ (Thaler and Sunstein 2009) who seek to steer patients’ and carers’ conduct along certain preferred treatment paths?

Healthcare is undergoing profound change under neoliberal policies that aim to reduce the role of government in all spheres of life and to deregulate markets. This includes efforts to wind back welfare provisions in many countries and to ‘downsize’ and outsource services, to casualise and ‘offshore’ labour, to ascribe a greater role to competitive tendering in the provision of services, and to encourage citizens to become more responsible and active in their own health, risk management, decision-making, and care, as supposed ‘empowered’ consumers. However, as we emphasise—despite the focus on active, empowered citizenship—in practice, individuals do not conduct themselves as ideal ‘consumers’ who exercise ‘choice’ via a rational ‘weighing’ up of options in the light

of perfect knowledge about these possibilities, assumed by the implicit rational actor model of economics. The consumer-centric conception of the self is one dimensional in neglecting the contexts in which individuals live their lives. Healthcare actions, including decisions about treatments, occur in a milieu of imperfect knowledge; uncertainty; emotional experiences of fear, desperation, and hope; and widely shared beliefs about matters such as whether treatments are ‘risky’ or ‘worth the risk’, ‘what works’ or is likely to work, and who can and should be trusted. Increasingly, citizens who explore health information and treatments are reliant upon, and are compelled to invest their hopes and trust in remote others, whose motives may be unclear and whose claims are difficult, if not impossible, to verify. In this context, one may ask, are patients’ and carers’ hopes and trust misplaced? And, if so, what are the likely consequences, for individuals and their families, and for science itself?

In the following chapters, we explore the role of discourses of technological promise, hope, and expectation in the stem cell tourism market, and the implications for relations of trust that are crucial for new fields of research such as stem cell science and for healthcare in general. Stem cell treatments epitomise the promises, hopes, and expectations that are attached to the consumption of new biomedical technologies, namely the potential to effectively treat conditions that were in the past viewed as intractable (Brown 2003). However, stem cell treatments are seen to hold particular promise due to their capacity to regenerate diseased and damaged tissue. Among many scientists, policymakers, and patient communities, there is considerable optimism regarding the potential for stem cell science to lead to new treatments in the not-too-distant future. This is a field with a strong ‘translational ethos’, namely the belief that scientific findings will travel quickly from ‘bench top to bedside’ (Maienschein et al. 2008). Optimism in regard to the potential for regenerative medicine has a long history, and much longer than generally recognised (Maienschein 2011). However, breakthroughs in the field of stem cell research in the 1990s and early 2000s, and associated media coverage, heightened optimism among scientists, the wider community, and national policymakers, who have been grappling with the rising number of degenerative conditions associated with ageing populations while seeking to advance economies through the development of biomedical innovations. During this

time, the field has attracted considerable investment from governments and the private sector, with research oriented to both uncovering mechanisms of stem cell differentiation ('basic research') and developing therapies for particular conditions ('applied research'). The field has also attracted controversy, especially during the early years of research involving the use of human embryonic stem cells, since this particular aspect of stem cell research involves the destruction of that which has the potential to become human life. Right-to-life groups and the Catholic Church were prominent critics of human embryonic stem cell research during its emergent phase, labelling it 'immoral' while embracing 'adult' stem cell research—where cells are obtained from a patient's or a donor's organs and tissues—as the 'ethical' alternative with little regard to the differences in biological potential or clinical validation (Smith et al. 2006). More recently, the discovery that stem cells could be created directly from cells in the body, without having to destroy an embryo, and that these induced pluripotent stem cells (iPSC) share many of the same attributes as those of embryonic stem cells, has been hailed again as the 'ethical' alternative despite the significant ethical considerations that this discovery raises (Hyun 2010; MacGregor 2013).

Meanwhile, for patients and their families, who are often desperate for new treatments, the translational pathway from research to treatment is painfully slow. Apart from bone marrow or haematopoietic (blood)-based stem cell transplants used to build a blood or immune system for the treatment of certain conditions (e.g. leukemia, lymphoma), or corneal and skin grafting, there remain few clinically proven therapies available to them in hospitals and clinics in their home country (Daley 2012). Although hundreds of novel stem cell-based interventions are being explored in clinical trials, most remain at the very early stages of investigation where the focus is on demonstrating safety in a small number of patients with strict inclusion and exclusion criteria (Li et al. 2014). As a result, even if patients would like to participate in clinical research, this option may be beyond their reach. It is in this context that providers of unproven stem cell treatments have flourished, advertising treatments 'direct to consumers' via the internet for various conditions—neurological, autoimmune, orthopaedic, cosmetic, and degenerative—marketing an array of treatments allegedly based on human stem cells but with little

or no scientific evidence to support therapeutic claims or indeed that the procedures are safe. Exactly what health risks those contemplating stem treatments could be exposed to can be difficult to ascertain and are rarely openly acknowledged on providers' websites. Rather clinics and providers are presented as 'experienced', 'renowned', and 'acclaimed' specialists practicing 'state-of-the-art' medicine (Connolly et al. 2014). However, given that the treatments can be highly invasive, involving the injection of living cells into the patient's veins, the fluid around the brain and spinal cord or even directly into their heart or brain, it is not surprising complications have been reported. For example, patients with spinal cord injury were discovered to have developed meningitis—an inflammation of the membranes surrounding the brain and spinal cord—following the use of contaminated cells in China (Dobkin et al. 2006). Other patients have been reported to develop a blockage in the lungs (pulmonary embolism), heartbeat irregularities, and the formation of tumours following stem cell treatments (Jung et al. 2013; Pytel et al. 2010; Amariglio et al. 2009; Barclay 2009; Thirabanjasak et al. 2010; Dlouhy et al. 2014). There have also been reports of deaths as a consequence of the highly invasive techniques used by the clinics to administer the cells (Cyranski 2010; Tuffs 2010; Pepper 2012). Although such reports are rare, they highlight the uncertainty about these procedures and the real possibility that the intervention could actually harm rather than help. In the chapters, we examine how the hopes and expectations attached to stem cell treatments are engendered, and how relations of trust that underpin decisions to pursue such treatments are established and sustained.

As our research has revealed, among those seeking stem cell treatments the language of hope is pervasive and, we argue, has been extensively used by those advertising new treatments. In the chapters, we explore how discourses of hope emerge, circulate, and are sustained and shape actions and how they contribute to the generation of expectations regarding treatments. The concept of the 'political economy of hope' originally used in relation to oncology treatment (DelVecchio Good et al. 1990; DelVecchio Good 2007), and subsequently in the context of patient activism in regard to genetic research (Rose and Novas 2005), we believe, usefully captures the entangling of individual aspirations and actions with wider sociocultural and politico-economic processes, including efforts to

bringing new treatments to market, and consequently provides a framework for our analysis. The political economy of hope is sustained by the actions of many constituencies, including scientists, clinicians, patients, the biotech industry, and governments that have some stake in the future promised by stem cell science. However, as we shall see, these different parties have very different investments in this future and different conceptions of when and how research will find practical application.

In this chapter we discuss the details of the research upon which this book draws and introduce the chapters that follow. To begin, however, we locate ‘stem cell tourism’ within the wider landscape of health and medical travel and global healthcare.

## Stem Cell Tourism in the Context of the Health and Medical Travel Industry

Stem cell tourism is part of a growing and highly diverse global health and medical travel industry, including specialties such as spa and wellness tourism, cosmetic and dental tourism, organ transplant tourism, and reproductive tourism. This sector comprises, apart from the doctors, hospitals and clinics themselves, and supporting staff, various advisory, insurance, marketing, and conference and events management services, interpreter and ‘concierge’ services (e.g. arranging accommodation and pickup from airport), and travel agencies. The health and medical travel industry even has its own publication, *The International Medical Travel Journal*, established in 2007. There are now education and training courses in health and medical tourism, underlining the professionalisation of the sector (IMTJ 2015a). According to one estimate, the global medical tourism market was valued at \$US10.5 billion in 2012 and was predicted to grow to \$US32.5 billion by 2019, or a mean annual growth rate of approximately 18 per cent (BioSpectrum Asia 2013). It is an industry that many governments have been keen to nurture as a significant value-adding component of ‘the bioeconomy’ (Petersen and Krisjansen 2015: 30).

The origins of ‘stem cell tourism’ as a concept and niche market within this global health and medical travel industry are obscure. In Australia, the first news article on ‘stem cell tourism’ appeared in July 2009 in *The Weekend Australian*:

A burgeoning international stem cell tourism industry is luring vulnerable people into embarking on stem cell therapy that has not been subjected to any of the usual stringent safety protocols, including clinical trials, that apply to potential new medical treatments. The internet is filled with websites offering purported stem cell treatments for conditions that conventional medicine as yet has no cure for. (Davies 2009)

However, the term ‘stem cell tourism’ was used earlier. A 2006 news article in the Hong Kong–based *South China Morning Post* reported that a Bangkok hospital was undertaking stem cell therapies using cells from the patient’s own blood (Montlake 2006). As the article noted:

The procedure uses stem cells grown from samples of the patient’s blood, which are processed at a laboratory in Israel and flown back to Bangkok. The cells are then injected into the patient’s heart. It is an experimental technique that is only performed in a few countries, and is usually offered to patients with severe heart failure, whose only alternative is a transplant.

Reflecting the sensitivities surrounding the use of human embryos in stem cell research and treatments at the time, this article notes that the hospital offering this treatment ‘doesn’t use embryonic cells, which generate the most controversy from campaigners who say embryos are human life’ (Montlake 2006).

In the following year, 2007, *The Scotsman*, reported that a patient who had lost his sight 24 years previously, due to a rare hereditary condition, was seeking a stem cell treatment (described as a “revolutionary” therapy) in the Netherlands. It noted: ‘[S]pecialists in the UK are concerned about premature applications of this technology, and warn that “stem-cell tourism”—the practice of going abroad for treatments not yet permitted in this country—could not only raise false hope in desperately vulnerable people, but also put them at serious risk of further complications.’ The article also noted that the clinician provider, who had clinics in London and in Holland was ‘currently under investigation by the General Medical Council in Britain and the Dutch health authorities, for prescribing stem-cell treatments which are unproven and unvalidated’ (*The Scotsman* 2007).

It is difficult to estimate the overall number of patients who have travelled to receive medical treatment of any kind, let alone the proportion of these who undertake specifically stem cell treatment, due to a lack of

verifiable data at the country level and inconsistencies in defining medical travel. Currently, there are no national registries of medical travellers, or a universal requirement to obtain a ‘medical treatment’ visa from the country where they seek treatment, nor a mandate for travellers to disclose that they have sought treatment upon returning home. Hence there is no mechanism for recording data on medical travellers that would provide a picture of the growth and character of the market. Market researchers provide various estimates of medical travel, broken down by the country of destination and the type of treatment, but these estimates vary between companies and should be viewed with caution. *Patients Beyond Borders*, which provides consumer information on health and medical travel, estimated in 2014 that approximately 11 million patients travel across borders, spending an average of \$US3,500 to 55,000 per visit, including all medical costs, transport, inpatient stay, and accommodation; 1.2 million Americans alone were estimated to travel abroad for medical care in 2014 (Patients Beyond Borders 2015a). In the UK, The International Passenger Survey undertaken for the Office of National Statistics estimated that 200,000 UK patients would travel abroad for medical treatment in 2015 (IMTJ 2015b). However, this figure is considered conservative and unreliable, as the Survey is drawn from a small sample size, based on asking people about the purpose of their travel of which medical reasons are a minute proportion; the Survey does not differentiate between those who do and those who do not view their trip as primarily for leisure (IMTJ 2015b). While ‘stem cell tourism’ can be considered to be an integral element of a burgeoning global health and medical travel market, its contribution to total patient traffic is unknown and, given the definitional and technical challenges in collecting such data, it is probably unknowable. In terms of *qualitative* criteria, however, stem cell tourism has some characteristics that distinguish this form of medical travel.

First, while the term ‘tourism’, which implies some recreational activity (usually in some purportedly exotic location) accompanying treatment, may apply to some forms of health and medical travel—perhaps most notably cosmetic tourism and spa and wellness tourism—this is generally not the case with stem cell tourism. As we shall see, those patients who embark on such treatments typically are those suffering severe,