

VU Research Portal

Implementing carrier screening in a changing landscape

Holtkamp, K.C.A.

2017

document version

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Holtkamp, K. C. A. (2017). *Implementing carrier screening in a changing landscape: Perspectives of public and professional stakeholders*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

TABLE OF CONTENTS

Chapter 1	General introduction and outline of the thesis	9
PART I	EVALUATION OF ANCESTRY-BASED CARRIER SCREENING IN DUTCH HIGH-RISK GROUPS	28
Chapter 2	Experiences of a high-risk population with prenatal haemoglobinopathy carrier screening in a primary care setting: a qualitative study <i>Submitted</i>	31
Chapter 3	Direct-to-consumer carrier screening for cystic fibrosis via a hospital website: a six-year evaluation <i>Submitted</i>	53
Chapter 4	Preconception carrier screening for multiple disorders: evaluation of a screening offer in a Dutch founder population <i>Submitted</i>	71
Chapter 5	Do people from the Jewish community prefer ancestry-based or pan-ethnic expanded carrier screening? <i>Eur J Hum Genet 2016;24:171-177</i>	91
PART II	IMPLEMENTATION OF CARRIER SCREENING IN A CHANGING LANDSCAPE	110
Chapter 6	Factors for successful implementation of population-based expanded carrier screening: learning from existing initiatives <i>Eur J Public Health 2017;27:372-377</i>	113
Chapter 7	Stakeholder perspectives on the implementation of genetic carrier screening in a changing landscape <i>BMC Health Services Research 2017;17:146</i>	131
Chapter 8	Advantages of expanded universal carrier screening: what is at stake? <i>Eur J Hum Genet 2017;25:17-21</i>	153

PART III	GENERAL DISCUSSION & SUMMARY	168
Chapter 9	General discussion	171
Chapter 10	Summary - Samenvatting	191
Addendum	Dankwoord	209
	About the author	213
	List of publications	215
	Appendices	219