

## Table of Contents

Foreword .....	5
Acknowledgements .....	5
Abbreviations and Acronyms .....	7
1. Introduction .....	8
2. PTC Tool Kit – Planning Phase .....	13
2.1. Strategy Checklist .....	13
2.2. Budget Considerations .....	15
2.3. Governance Framework .....	17
3. PTC Tool Kit – Stakeholder Engagement Phase .....	18
3.1. Communications Strategy .....	18
3.2. Privacy FAQs .....	21
3.3. Research Ethics FAQs .....	24
3.4. Clinical Operations FAQs .....	28
3.5. Researcher FAQs .....	30
4. PTC Tool Kit – Development Phase .....	31
4.1. Protocol Template .....	31
4.2. Data Management .....	34
4.3. Participant Materials .....	37
5. PTC Tool Kit – Implementation Phase .....	39
5.1. Staff Training Materials .....	39
5.2. Research Utilization .....	41
5.3. Monitoring and Evaluation .....	43
6. Other Resources Available .....	45
6.1. The Biobank Resource Centre .....	45
6.2. Useful Websites .....	46
6.3. Contacts .....	47
7. Glossary .....	48
8. References .....	54

9. Appendices.....	56
Appendix A – Survey Approach and Questions.....	56
Appendix B – Summarized Survey Data .....	59
Appendix C – Governance SOP Template .....	63
Appendix D – Documenting Participation SOP Template .....	67
Appendix E – Withdrawal of Participation SOP Template .....	71
Appendix F– Example PTC Process Map .....	79
Appendix G – Full list of PTC Database Application Fields and Definitions .....	80
Appendix H – Examples of Participant Materials.....	82
Appendix I – Example Research Application Form .....	92
Appendix J – Example Telephone Script When Contacting PTC Participants .....	93