

**Appendix I. Literature search (performed April 2019)**

<b>Database</b>	<b>Search string</b>	<b>#hits</b>
PubMed	(((((patient*[Title/Abstract] OR public*[Title/Abstract] OR citizen*[Title/Abstract])) AND (view*[Title/Abstract] OR attitude*[Title/Abstract] OR perspective*[Title/Abstract] OR opinion*[Title/Abstract] OR interview*[Title/Abstract] OR qualitative[Title/Abstract] OR survey*[Title/Abstract] OR questionnaire*[Title/Abstract])) AND ("data sharing"[Title/Abstract] OR "data access"[Title/Abstract] OR "data transfer"[Title/Abstract])) AND research[Title/Abstract])	318
Scopus	TITLE-ABS ( patient* OR public OR citizen* ) AND TITLE-ABS ( view* OR perspective* OR attitude* OR opinion* OR interview* OR qualitative OR questionnaire* OR survey* ) AND TITLE-ABS ( "data sharing" OR "data access" OR "data transfer" ) AND TITLE-ABS ( research )	395
Embase	(patient*:ab,ti OR public:ab,ti OR citizen*:ab,ti) AND (attitude*:ab,ti OR view*:ab,ti OR perspective*:ab,ti OR opinion*:ab,ti OR interview*:ab,ti OR qualitative:ab,ti OR survey*:ab,ti OR questionnaire*:ab,ti) AND ('data sharing':ab,ti OR 'data access':ab,ti OR 'data transfer':ab,ti) AND research:ab,ti	355
Google Scholar	allintitle: patient data perspectives OR attitudes OR views OR opinions	85