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**Larson, H. J., Clarke, Richard ORCID logoORCID:
<https://orcid.org/0000-0002-1060-3142>, Jarrett, C.,
Eckersberger, E., Lavine, Z., Schulz, W. and Paterson, P. (2018)
Measuring trust in vaccination: A systematic review. *Human
Vaccines and Immunotherapeutics*, 14 (7). pp. 1599-1609.
doi:10.1080/21645515.2018.1459252**

Official URL: <https://doi.org/10.1080/21645515.2018.1459252>

DOI: <http://dx.doi.org/10.1080/21645515.2018.1459252>

EPrint URI: <https://eprints.glos.ac.uk/id/eprint/10983>

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Publisher: Taylor & Francis

Journal: *Human Vaccines & Immunotherapeutics*

DOI: <https://doi.org/10.1080/21645515.2018.1459252>

Measuring trust in vaccination: A systematic review

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Abstract

Vaccine acceptance depends on public trust and confidence in the safety and efficacy of vaccines and immunization, the health system, healthcare professionals and the wider vaccine research community. This systematic review analyses the current breadth and depth of vaccine research literature that explicitly refers to the concept of trust within their stated aims or research questions. After duplicates were removed, 19,643 articles were screened by title and abstract. Of these 2,779 were screened by full text, 35 of which were included in the final analysis. These studies examined a range of trust relationships as they pertain to vaccination, including trust in healthcare professionals, the health system, the government, and friends and

family members. Three studies examined generalized trust. Findings indicated that trust is often referred to implicitly (19/35), rather than explicitly examined in the context of a formal definition or discussion of the existing literature on trust in a health context. Within the quantitative research analysed, trust was commonly measured with a single-item measure (9/25). Only two studies used validated multi-item measures of trust. Three studies examined changes in trust, either following an intervention or over the course of a pandemic. The findings of this review indicate a disconnect between the current vaccine hesitancy research and the wider health-related trust literature, a dearth in research on trust in low and middle-income settings, a need for studies on how trust levels change over time and investigations on how resilience to trust-eroding information can be built into a trustworthy health system.

Keywords: trust, confidence, vaccines, vaccination, immunization/immunisation

INTRODUCTION

Trust in the safety and efficacy of vaccines, trust in the individuals that administer vaccines or give advice about vaccination, and trust in the wider health system are all important factors which influence the vaccine decision-making process (1–3). Trust is especially important in light of the increasing number of vaccines recommended or required, as well as the complex safety and efficacy data that form the basis of vaccine policies and recommendations, which means that the public depends on health experts' competence, judgement and ability to interpret these data correctly and in the best interests of the public (4–9). Due to this complexity, vaccination decisions occur within the context of trust held in the various actors who interpret and make decisions based on the available evidence (10).

Vaccine-related trust also exists within the additional context of deeper, underlying trust in society at large. The historical legacy of trust/mistrust due to past interactions with official institutions additionally influences generalized trust in society (see figure 1). These varied

histories and experiences mean that public trust in vaccines and immunization programs is highly variable and locally specific (11). Recognizing trust as a complex web of vaccine-related factors, as well as these external trust factors, can provide valuable insights into levers of vaccine acceptance, hesitancy or refusal.

Definitions of trust

The word 'trust' has been given a multitude of definitions within the health literature. At its core, trust becomes important when there is an implicit imbalance of power due to a high level of information asymmetry, where trusting individuals accept a vulnerable position in relation to a trusted party. In the context of vaccine decisions, one chooses to trust another to help make a risk/benefit-based decision about which one has incomplete information (12–14).

Trust relationships require an active choice on behalf of the trusting party. Within this choice, trust-based cooperation assumes the trusted party firstly has the trusting individuals' best interests at heart and, secondly, has the expertise and ability to perform at a level of competence that is expected of them (15). As such, the process of trusting is sometimes described as a leap of faith (15,16).

We define trust as a relationship that exists between individuals, as well as between individuals and a system, in which one party accepts a vulnerable position, assuming the best interests and competence of the other, in exchange for a reduction in decision complexity.

Trust relationships related to vaccination

Vaccine acceptance involves multiple levels of trust: trust in the **product** (the vaccine), the **provider** (the specific healthcare professionals or administrative staff that are involved in providing and administering vaccination), and trust in the **policy-maker** (the health system,

government, and public health researchers involved in approving and recommending the vaccine) (17).

Trust in information needs to be considered at multiple levels – i.e. trust in the information itself (13,18,19) as well as trust in those who produce and propagate the information (20,21). In this review, we consider trust in information as nested within the trust held in the source of that information (18). Each source of information also possesses attributes that inform one's assessment of its trustworthiness and reliability (22). Finally, perceptions of trustworthiness are subjective, since the same person or institution may be ascribed different levels of trustworthiness by different individuals, depending on those individuals' personal experiences and biases (23).

[Figure 1]

External levers of trust

In addition to influences on trust in the context of immunization, there are a number of external factors that influence trust.

Generalized trust

Generalized trust refers to the characteristic trait that differs between individuals with regard to their willingness to trust other members of society in general (24). When community-mindedness and civic participation are widespread in a society with high average levels of trust, the concept of *generalized trust* forms part of the wider concept of *social capital*.

Historically, generalized trust has been said to play an important role in the flow of information from official sources to individuals in a community (25,26).

Historical influences on trust

How a health system has performed in the past, and the perceived values that it holds, play a substantial role in the process of building trust. Earle, Siegrist & Gutscher (27) describe the dual concepts of *social trust* and *confidence* within their TCC Model of Trust, Confidence and Cooperation (27–29). *Social trust*, closely relates to the similar concepts of benevolence, fidelity and morality in that its main requirement is a perceived set of shared values between individuals and a trusted party. *Confidence*, conversely, is described as the performance-based aspect of trust in which the competence and ability of the trusted party is assessed. If, therefore, a system is seen to discriminate against a particular population over a sustained period of time, it is likely that that population will lose trust in the system, which has implications for trusting and accepting the health information and interventions it provides in the future.

Religious and ethnic minorities are frequently cited in the healthcare trust literature as holding lower levels of trust in the health system and healthcare professionals (HCPs) (30–32). This distrust can be traced back to historical mistreatment and systematic neglect or abuse of these populations by health and governmental systems (33,34).

External influencers

Non-official sources of health information also influence decision making (35,36). Trust in these sources depends on perceived motive (*Do the sources have my interests at heart?*) and ability (*Have they been competent and reliable in the past?*). These external influencers can include an individual's own friends and family members, and non-official medical advice from religious organizations, alternative health networks, politicians and celebrities.

Mechanisms by which trust-based cooperation is built or eroded

Vaccination-related trust is considered in this review as a complex interaction between the core elements of trust in the product, provider and policy-maker and the external levers of

trust – generalized trust, historical trust and other influences outside of the health system (see figure 1). Trust related to vaccination is strengthened when external levers align with the vaccine-related trust factors, and it is weakened when these are misaligned. If trust is lost in the vaccine-related players, then trust is more likely to be placed in other influencers, who may be indifferent to vaccination or may actively oppose it.

OBJECTIVES

The objectives of this systematic review are to:

- (1) Investigate how studies conceptualize and measure the concept of trust as a prominent factor in vaccine intention or uptake;
- (2) Discuss how the research compares to the wider literature on trust in the context of health decisions; and
- (3) Investigate the different dimensions of trust and their relationships as they influence vaccine uptake.

METHODS

Search strategy

Ten different medical and social science literature databases were searched for peer-reviewed articles on trust in vaccines or vaccination programs. These databases were Medline, Embase, PsychInfo, Cochrane, CINAHL Plus, Web of Science, LILACS, Africa-Wide Information, IBSS and IMEMR. Other than the time periods covered by each database, no additional time limitations were set.

A set of keywords was created to reflect the core concepts: vaccination and public perceptions, decision-making, and vaccination behaviour. Using Medline as a foundation database, these keywords were first refined and then systematically adapted (e.g. alternative

truncations) and applied to the remaining databases. Adaptations were extended to subject headings and descriptors where appropriate.

In Medline, the keyword search terms were: vaccin\$, immunis\$ and immuniz\$ (Concept 1) and anxiety, attitude\$, awareness, behavior?, belief\$, criticis\$, doubt\$, distrust\$, dropout\$, exemption\$, fear\$, hesitanc\$, trust, mistrust, perception\$, refusal\$, rejection, rumo?r, intent\$, controvers\$, misconception\$, misinformation, opposition, delay, dilemma\$, objector\$, uptake, barrier\$, choice\$, mandatory, compulsory, concern\$, accepta\$, knowledge, parent.\$ con\$, confidence, decision making, anti-vaccin\$, antivaccin\$.

The following MeSH terms were also included in the search: Vaccination, Vaccines, Mass Vaccination, Immunization and Immunization Programs and Public Opinion, Attitude to Health, Attitude, 'Health Knowledge, Attitudes, Practice', Patient acceptance of health care, Treatment Refusal, Parental Consent, Decision Making, Prejudice and Internet.

The search was run across all databases during the period 12-19 November 2012 and again on 15 December 2014. We conducted a final update to this review on 17 November 2017 for which we used a reduced version of the previous search terms, including only (vaccin\$ or immunis\$ or immuniz\$) and (distrust\$ or trust or mistrust or rumo?r) and narrowed the year range to 2015-2017.

[Figure 2]

Study selection

Studies were included if they met the following criteria: (i) they included research on trust/distrust, perceptions, concerns, confidence, attitudes, beliefs about vaccines and vaccination programs; (ii) they were published in a peer-reviewed journal; (iii) they were written in English.

Literature was excluded if it was: (i) about non-human vaccines or vaccines not currently available; (ii) related to research and development of vaccines (unless explicitly about public trust, confidence, concern or hesitancy); (iii) non-peer-reviewed or non-research papers.

The screening of titles and abstracts was shared between at least two authors and a sample of studies was independently coded to ensure consistency.

Data extraction

The included papers were assigned a numerical trust code based on the following criteria:

- Code 1: Primary research question about trust.
- Code 2: Trust referred to as a dimension, factor or variable (i.e. trust is identified in the results or named as a determinant related to vaccine acceptance, although not explicitly investigated in the research question).
- Code 3: Trust is mentioned in a peripheral way (e.g. in discussion section, but not in methods or results).
- Code 4: No reference to trust.

The papers coded as trust code 1 were then screened by full text, and only papers with research questions specifically about trust were included in our analysis. A data extraction form was developed by the authors. Information extracted included details about the study country, vaccine, population of focus, study methodology and trust factor (e.g. the health system, health care professional, the government etc.).

[Table 1: Characteristics of quantitative studies]

[references in order of table (37–64)]

[Table 2: Characteristics of qualitative studies]

[references in order of table (65–71)]

RESULTS

After duplicates were removed, 19,643 articles were screened by title and abstract and 2,779 articles were screened by full text. Thirty-five articles were included in the analysis.

Characteristics of studies

Of the 35 included studies, over half (21/35) were conducted in the USA. Two studies were conducted in Taiwan, one study was in India, and one in Japan. The remaining nine studies were conducted in either Western Europe or Australia. The target vaccine/vaccination program varied between studies with 11 studies focusing on childhood vaccinations (standard vaccine schedule or specifically MMR, rotavirus, or influenza vaccine), 14 studies focusing on adult vaccinations (HPV, seasonal influenza, pandemic influenza, postpartum pertussis, smallpox, or anthrax vaccine) and three studies focusing on the adolescent HPV vaccination. Investigated trust factors predominantly included the information from and/or the trust placed in the health system, healthcare professionals, the government, science or trusted others (e.g. friends, family, alternative healthcare professionals, non-official internet sources, celebrities). Three studies investigated the concept of *generalized trust*.

Quantitative studies

Context of trust

Of the 28 quantitative studies reviewed, ten studies examined trust in the context of vaccine uptake, six studies examined trust in the context of intention to vaccinate, ten studies examined factors associated with vaccine trust and two studies examined HCPs trust in the health system and their likelihood to give a strong recommendation to vaccinate. Findings from these studies indicated that combined trust in the health system, trust in science and trust in government have an indirect effect on the likelihood of HCPs recommending vaccination (56).

All studies measured some aspect of vaccination trust (see figure 1). Factors outside of the specific vaccine or vaccination program were measured less frequently, with three studies examining generalized trust (40,45,57), three studies examining out-of-program influences (44,54,61) and one study examining changes in trust over time (62). Wada and Smith (61) was the only study to have referenced the concept of trustworthiness and its findings indicated that respondents who did not trust a vaccination recommendation were more likely to consider other non-medical sources as being trustworthy.

Definition and Measurement overview

Eighteen of the quantitative studies did not contain a definition of trust or a discussion of the concepts present within the trust literature, despite explicitly mentioning trust within their aim or research question (37,39,41–44,46,48,49,51–54,56,58,60,61,64). By leaving the definition of trust implicit, these papers created ambiguity around this core concept. Four studies (38,47,50,63) included some brief mentions of relevant trust concepts (e.g. a distinction between social trust and confidence). Only six studies defined trust through extensive reference to previously published peer-reviewed trust literature (40,55,57,59,62,72).

[Table 3: Definitions of trust across research context]

Among the 25 studies that reported their measures, only three used previously validated or widely used measures of trust (49,57,60). Five studies constructed measures of trust explicitly informed by published trust literature (40,50,59,62,72). A further five studies, while not explicitly mentioning the trust literature, used metrics that reflected aspects of confidence and social trust as they are conceptualized in the literature (38,52,58,63,64). The remaining studies (10 of 25) measured trust with a single-item measure that either asked the respondents to indicate their level of trust in the trust subject (e.g. individual services, or the system) or in the information provided (39,41,43,44,46,48,54–56,61).

[Table 4: The use of measurement across research context]

[Footnote: A full reporting of measures used can be found in the supplemental materials]

Studies focused on vaccination uptake

Within the quantitative studies that examined the relationship between trust and vaccine uptake 7/10 studies reported measuring trust in the health system, 5/10 reported measuring trust in primary HCPs, 4/10 reported measuring trust in government and 1/10 reported measuring *generalized trust*. No studies focusing on vaccine uptake examined other subjects of trust such as trust in science, trust in the media or trust in influential individuals outside the immunization system (such as friends and family, religious or community leaders, celebrities, alternative healthcare professionals).

Trust in the health system was reliably found to predict vaccine uptake in regression analyses (47,51) or was found to be significantly associated with retrospective reports of a vaccine uptake (38,39,43,49). A positive association was also identified between trust in HCPs and vaccine uptake in 4/6 studies measuring this factor (38,46,50,51).

Three out of the four studies that examined trust in government found a significant positive association between trust and vaccine uptake (38,46,50). The one study (57) investigating *generalized trust* found a significant positive association between generalized trust and vaccine uptake.

One study used a validated trust measure (49) – the Group-Based Medical Mistrust Scale (73). Ronnerstand (57) and Lee et al (50) used the standard *generalized trust* question (24) and use an adapted version of the Trust in Physician Scale (74) respectively.

Studies focused on 'intention to vaccinate'

Among the six studies that investigated intention to vaccinate, trust in the health system was the most-measured trust factor (4/6 studies) (52,59,60). Two studies measured trust in governments (40,62), one study measured trust in HCPs (52) and one study measured generalized trust (40). All trust factors measured were found to be positively associated with an increased intention to vaccinate.

Three of the studies made a distinction between *social trust* and *confidence* (59,60,62), one of which mentions the TCC Model of Trust, Confidence and Cooperation specifically (62). One study used a validated trust measure (60) in the form of the Health Care System Distrust Scale (75).

Additionally, an experimental study by Scherer et al (58) indicated that showing individuals a summary of the vaccine adverse effect data slightly increased trust in the health system, however showing detailed reports greatly reduced trust.

Studies that measured factors associated with vaccine trust

In ten studies, multiple trust factors were identified (37,41,48,54,64) and formed the primary focus of the study (44,55,61,63,72). Measurement of trust within this subset of studies did not utilize validated measures of trust or explicitly use the existing trust literature to inform their measurement items.

Factors associated with a lower level of trust in the health system or a HCP included being in a lower income bracket (63,64) and belonging to an ethnic minority (41,55,63,72). While factors such as previous participation in a school-based immunization program (63), perceived importance of the vaccine (63), and the use of Medicaid (US) over private insurance (63) were associated with higher levels of trust in the health system or a HCP. Further findings indicated a range of subjects that were trusted to different degrees by the respondents (44,54,61).

Studies focused on healthcare professionals

Two studies with a focus on trust from the perspective of HCPs met our inclusion criteria (53,56). Of these, one focused primarily on trust (56) and the other explored a range of vaccine acceptance factors, including trust (53). Neither of the two studies utilised validated measures of trust, nor did they explicitly use previous trust literature to inform the development of their measures.

Qualitative Studies

The findings from the qualitative studies were generally more representative of the wider trust literature than those of the quantitative studies. Of the seven qualitative studies, four studies thoroughly defined the concept of trust with reference to peer-reviewed literature (65,66,70,71) and a further two studies referenced at least some of the healthcare-trust literature (68,69). Only in one study was the definition of trust left implicit (67).

One of the common themes reported was the interaction between trust, information and conflicts of interest due to financial incentives. A perceived trust violation was said to occur when HCPs, the government or the wider health system were seen to financially profit from vaccination which, in turn, often led to a perception of bias in the information provided by these individuals or institutions. Perceived trust violations were reported in four of the seven studies (65,66,68,70), one of which indicated that HCPs themselves cited financial incentives as possibly damaging the trust relationships with their patients (65). Hilton, Petticrew & Hunt (68) suggest that when financial incentive-based mistrust occurs, trust may then be transferred to other trusted parties that are perceived to be free of any 'hidden agenda.'

Further findings from Harris et al (67) and Quinn et al (71) indicate that mistrust in the health system by African Americans may be a symptom of long-term experiences of racial prejudice.

Historical medical injustices and medical malpractice were seen to negatively affect trust; however, trust was said to recover when medical care was good over time (69).

DISCUSSION

Measurements of trust

The absence of validated psychometric measures of trust

A 2013 systematic review by Ozawa & Sripad (76) on the measurement of health-related trust identified and evaluated 45 validated multi-item measures of health system related trust.

Within our vaccine-specific review only three studies (49,50,60) used or adapted any of the trust measures included in the Ozawa & Sripad review, indicating a disconnect between vaccine-related trust research and the wider health-related trust literature.

This lack of underlying theory and validity with respect to the measurement of trust was also prevalent across many of the studies that constructed their own measures. For example, 10 out of the 25 studies that reported their measures cited the use of a single question to measure an aspect of trust, many of which dichotomized their Likert scale variable for later analysis further reducing the sensitivity of their findings.

Within the qualitative research, it was evident that distrust based on value misalignment was particularly likely when HCP financial incentives for vaccinating were identified (65,66,68,70). This form of distrust is distinct from the distrust caused by perceptions of incompetence. Currently this distinction is left largely unexamined by much of the vaccine-related trust research. The inclusion of a validated psychometric scale or the custom design of two trust questions (one related to perceived performance/reliability and one related to perceived motives and morality/values of a trusted party), would allow for a far more nuanced exploration of these different trust dynamics.

Measurement focused on trust in the health system or healthcare professionals

While trust is shown to have a positive effect on vaccination intention and uptake in most of the studies reviewed, few explored trust factors or concepts beyond those of trust in the health system (21 studies), the government (10 studies) or HCPs (9 studies). Only two studies (42,52) specifically measured trust in the vaccine (e.g. ‘Overall, how much do you trust the flu vaccine?’ (42)). Furthermore, factors outside of the vaccination program were also rarely measured (40,44,54,57,61,62,72). Future research would benefit greatly from investigating further interactions between the various dimensions of trust related to vaccination.

Historic trust and under representation of low- and middle-income countries

The theme of historic neglect or abuse from a government or health system was often seen as an underlying reason for distrust in vaccines among marginalized groups (67,69,71). Some of the quantitative studies examined these themes through the comparison of trust levels between different ethnic groups (45,46,49,54,55). While this is without doubt an important topic to study, the equally important concept of trustworthiness of the systems themselves is noticeably absent. By shifting the burden of distrust onto the minority individual or community, and away from the trustworthiness of institutions, the genuine drivers of trust and distrust may actually be obscured.

The level of diversity within the studies that met our inclusion criteria reflects a narrow focus on high-income countries. Only one study was based in a middle-income country (42) and none of the studies focused on low-income countries. With trust playing such a key role in influencing vaccine acceptance, more research is needed in middle and low-income settings to truly understand whether findings in high-income countries have relevance in low and middle-income countries.

Limitations

This review was conducted over a five-year period with periodic updates. While this resulted in the inclusion of a greater number of relevant studies, it is possible that some relevant papers may have been missed between updated searches, even with the addition of snowball searching and peer-recommendations for additional papers.

For the purpose of this review, only those papers that mentioned trust within their research aim or question were included. This therefore does not cover the full extent of the relationships that exist between trust and vaccination but instead focuses on those studies that made trust the specific focus of their research. Conclusions drawn from this review should therefore be limited to the methodology and extent of measurement within these studies rather than be taken as a full overview of trust's influence on vaccination.

CONCLUSION

Even within vaccine studies that include the concept of trust within their primary research question, trust can often be an ill-defined and loosely measured concept. The prevalence of single-item measures, where the definition of trust was left as implicit, indicates that a thorough understanding of trust as it relates to vaccine acceptance is currently under-researched. Furthermore, a lack of experimental or longitudinal studies that investigate how trust can be eroded or built over time demonstrates that there is great potential for new contributions to our understanding of the temporal dynamics and levers of trust in relation to vaccination.

Acknowledgements

We would like to thank Jay Dowle and Roshan Daryanani for their help in the process of this review.

References

1. Larson HJ, Jarrett C, Eckersberger E, Smith DM, Paterson P. Understanding vaccine

- hesitancy around vaccines and vaccination from a global perspective: a systematic review of published literature, 2007–2012. *Vaccine*. 2014 Apr 17;32(19):2150-9.
2. Paterson P, Meurice F, Stanberry LR, Glismann S, Rosenthal SL, Larson HJ. Vaccine hesitancy and healthcare providers. *Vaccine*. 2016 Dec 20;34(52):6700-6.
 3. Thomson A, Robinson K, Vallée-Tourangeau G. The 5As: A practical taxonomy for the determinants of vaccine uptake. *Vaccine*. 2016 Feb 17;34(8):1018-24.
 4. Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green J, Long SJ, Vincent CA, Fraser G, Sevdalis N. Factors underlying parental decisions about combination childhood vaccinations including MMR: a systematic review. *Vaccine*. 2010 Jun 11;28(26):4235-48.
 5. Larson H, Schulz W. The state of vaccine confidence 2015. London: London School of Hygiene & Tropical Medicine. 2015.
 6. Schmid P, Rauber D, Betsch C, Lidolt G, Denker ML. Barriers of influenza vaccination intention and behavior—a systematic review of influenza vaccine hesitancy, 2005–2016. *PloS one*. 2017 Jan 26;12(1):e0170550.
 7. Serpell L, Green J. Parental decision-making in childhood vaccination. *Vaccine*. 2006 May 8;24(19):4041-6.
 8. Vaughan E, Tinker T. Effective health risk communication about pandemic influenza for vulnerable populations. *Am J Public Health*. 2009 Oct;99(S2):S324-32.
 9. Jackson C, Cheater FM, Reid I. A systematic review of decision support needs of parents making child health decisions. *Health Expect*. 2008 Sep 1;11(3):232-51.
 10. Larson HJ, Cooper LZ, Eskola J, Katz SL, Ratzan S. Addressing the vaccine

- confidence gap. *The Lancet*. 2011 Aug 6;378(9790):526-35.
11. Larson HJ, de Figueiredo A, Xiaohong Z, Schulz WS, Verger P, Johnston IG, Cook AR, Jones NS. The state of vaccine confidence 2016: global insights through a 67-country survey. *EBioMedicine*. 2016 Oct 1;12:295-301.
 12. Hall MA, Zheng B, Dugan E, Camacho F, Kidd KE, Mishra A, Balkrishnan R. Measuring patients' trust in their primary care providers. *Med Care Research and Review*. 2002 Sep;59(3):293-318.
 13. Cummings L. The "trust" heuristic: Arguments from authority in public health. *Health Commun*. 2014 Nov 26;29(10):1043-56.
 14. Siegrist M, Earle TC, Gutscher H. Test of a trust and confidence model in the applied context of electromagnetic field (EMF) risks. *Risk Anal*. 2003 Aug 1;23(4):705-16.
 15. Möllering G. The nature of trust: From Georg Simmel to a theory of expectation, interpretation and suspension. *Sociology*. 2001 May;35(2):403-20.
 16. Brownlie J, Howson A. 'Leaps of faith' and MMR: an empirical study of trust. *Sociology*. 2005 Apr;39(2):221-39.
 17. Larson HJ, Schulz WS, Tucker JD, Smith DM. Measuring vaccine confidence: introducing a global vaccine confidence index. *PLoS currents*. 2015 Feb 25;7.
 18. Frewer LJ, Howard C, Hedderley D, Shepherd R. What determines trust in information about food- related risks? Underlying psychological constructs. *Risk Anal*. 1996 Aug 1;16(4):473-86.
 19. Ozawa S, Paina L, Qiu M. Exploring pathways for building trust in vaccination and strengthening health system resilience. *BMC Health Serv Res*. 2016 Nov;16(7):639.

20. Connolly T, Reb J. Toward interactive, Internet-based decision aid for vaccination decisions: better information alone is not enough. *Vaccine*. 2012 May 28;30(25):3813-8.
21. Trevena LJ, Zikmund-Fisher BJ, Edwards A, Gaissmaier W, Galesic M, Han PK, King J, Lawson ML, Linder SK, Lipkus I, Ozanne E. Presenting quantitative information about decision outcomes: a risk communication primer for patient decision aid developers. *BMC med inform decis*. 2013 Nov;13(2):S7.
22. Levi M, Stoker L. Political trust and trustworthiness. *Annu rev of polit sci*. 2000 Jun;3(1):475-507.
23. Hardin R. Trust and trustworthiness. *Pers Psychol*. 2003;56(1):263–5.
24. Bjørnskov C. The multiple facets of social capital. *Eur J Polit Econ*. 2006;22(1):22–40.
25. Gilson L. Trust and the development of health care as a social institution. *Soc sci med*. 2003 Apr 1;56(7):1453-68.
26. Rothstein B, Stolle D. The state and social capital: An institutional theory of generalized trust. *Comp polit*. 2008 Jul 1;40(4):441-59.
27. Earle TC, Siegrist M, Gutscher H. Trust, risk perception and the TCC model of cooperation. *Trust in risk management: Uncertainty and scepticism in the public mind*. 2010 Sep 23:1-50.
28. Siegrist M, Cvetkovich G, Roth C. Salient value similarity, social trust, and risk/benefit perception. *Risk anal*. 2000 Jun 1;20(3):353-62.
29. Twyman M, Harvey N, Harries C. Trust in motives, trust in competence: Separate factors determining the effectiveness of risk communication. *Judgm Decis Mak*. 2008

Jan 1;3(1):111.

30. Brandon DT, Isaac LA, LaVeist TA. The legacy of Tuskegee and trust in medical care: is Tuskegee responsible for race differences in mistrust of medical care?. *J Natl Med Assoc.* 2005 Jul;97(7):951.
31. Corbie-Smith G, Thomas SB, George DM. Distrust, race, and research. *Arch Intern Med.* 2002 Nov 25;162(21):2458-63.
32. Halbert CH, Armstrong K, Gandy OH, Shaker L. Racial differences in trust in health care providers. *Arch Intern Med.* 2006 Apr 24;166(8):896-901.
33. Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. *Public Health Rep.* 2016 Nov 15.
34. Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *Am J of Public Health.* 1997 Nov;87(11):1773-8.
35. Van den Brink-Muinen A, Rijken PM. Does trust in health care influence the use of complementary and alternative medicine by chronically ill people?. *BMC Public Health.* 2006 Dec;6(1):188.
36. Clarke TC, Black LI, Stussman BJ, Barnes PM, Nahin RL. Trends in the use of complementary health approaches among adults: United States, 2002–2012. *National health statistics reports.* 2015 Feb 10(79):1.
37. Berry JG, Gold MS, Ryan P, Duszynski KM, Braunack-Mayer AJ, Vaccine Assessment Using Linked Data (VALiD) Working Group. Public perspectives on consent for the linkage of data to evaluate vaccine safety. *Vaccine.* 2012 Jun 13;30(28):4167-74.

38. Casiday R, Cresswell T, Wilson D, Panter-Brick C. A survey of UK parental attitudes to the MMR vaccine and trust in medical authority. *Vaccine*. 2006 Jan 12;24(2):177-84.
39. Cheng PJ, Huang SY, Shaw SW, Kao CC, Chueh HY, Chang SD, Hsu TY, Kung FT. Factors influencing women's decisions regarding pertussis vaccine: A decision-making study in the Postpartum Pertussis Immunization Program of a teaching hospital in Taiwan. *Vaccine*. 2010 Aug 2;28(34):5641-7.
40. Chuang YC, Huang YL, Tseng KC, Yen CH, Yang LH. Social capital and health-protective behavior intentions in an influenza pandemic. *PLoS One*. 2015 Apr 15;10(4):e0122970.
41. Cooper DL, Hernandez ND, Rollins L, Akintobi TH, McAllister C. HPV vaccine awareness and the association of trust in cancer information from physicians among males. *Vaccine*. 2017 May 9;35(20):2661-7.
42. Das J, Das S. Trust, learning, and vaccination: a case study of a North Indian village. *Soc Sci Med*. 2003 Jul 1;57(1):97-112.
43. Fowler GL, Baggs JM, Weintraub ES, Martin SW, McNeil MM, Gust DA. Factors influencing laboratory workers' decisions to accept or decline anthrax vaccine adsorbed (AVA): results of a decision-making study in CDC's anthrax vaccination program. *Pharmacoepidem Dr S*. 2006 Dec 1;15(12):880-8.
44. Freed GL, Clark SJ, Butchart AT, Singer DC, Davis MM. Sources and perceived credibility of vaccine-safety information for parents. *Pediatrics*. 2011 May 1;127(Supplement 1):S107-12.
45. Freimuth VS, Jamison AM, An J, Hancock GR, Quinn SC. Determinants of trust in the

- flu vaccine for African Americans and Whites. *Soc Sci Med*. 2017 Nov 1;193:70-9.
46. Fu LY, Zimet GD, Latkin CA, Joseph JG. Associations of trust and healthcare provider advice with HPV vaccine acceptance among African American parents. *Vaccine*. 2017 Feb 1;35(5):802-7.
47. Gilles I, Bangerter A, Clémence A, Green EG, Krings F, Staerklé C, Wagner-Egger P. Trust in medical organizations predicts pandemic (H1N1) 2009 vaccination behavior and perceived efficacy of protection measures in the Swiss public. *Eur J Epidemiol*. 2011 Mar 1;26(3):203-10.
48. Grabenstein JD, Guess HA, Hartzema AG, Koch GG, Konrad TR. Attitudinal factors among adult prescription recipients associated with choice of where to be vaccinated. *J Clin Epidemiol*. 2002 Mar 1;55(3):279-84.
49. Kolar SK, Wheldon C, Hernandez ND, Young L, Romero-Daza N, Daley EM. Human papillomavirus vaccine knowledge and attitudes, preventative health behaviors, and medical mistrust among a racially and ethnically diverse sample of college women. *Journal of racial and ethnic health disparities*. 2015 Mar 1;2(1):77-85.
50. Lee C, Whetten K, Omer S, Pan W, Salmon D. Hurdles to herd immunity: Distrust of government and vaccine refusal in the US, 2002–2003. *Vaccine*. 2016 Jul 25;34(34):3972-8.
51. Manika D, Ball JG, Stout PA. Factors associated with the persuasiveness of direct-to-consumer advertising on HPV vaccination among young women. *J Health Commun*. 2014 Nov 2;19(11):1232-47.
52. Marlow LA, Waller J, Wardle J. Trust and experience as predictors of HPV vaccine acceptance. *Human vaccines*. 2007 Sep 1;3(5):171-5.

53. McPhillips HA, Davis RL, Marcuse EK, Taylor JA. The rotavirus vaccine's withdrawal and physicians' trust in vaccine safety mechanisms. *Arch Pediat Adol Med.* 2001 Sep 1;155(9):1051-6.
54. Moran MB, Frank LB, Chatterjee JS, Murphy ST, Baezconde-Garbanati L. Information scanning and vaccine safety concerns among African American, Mexican American, and non-Hispanic White women. *Patient Educ Couns.* 2016 Jan 1;99(1):147-53.
55. Quinn SC, Jamison A, Freimuth VS, An J, Hancock GR, Musa D. Exploring racial influences on flu vaccine attitudes and behavior: Results of a national survey of White and African American adults. *Vaccine.* 2017 Feb 22;35(8):1167-74.
56. Raude J, Fressard L, Gautier A, Pulcini C, Peretti-Watel P, Verger P. Opening the 'Vaccine Hesitancy' black box: how trust in institutions affects French GPs' vaccination practices. *Expert Rev Vaccines.* 2016 Jul 2;15(7):937-48.
57. Rönnerstrand B. Social capital and immunisation against the 2009 A (H1N1) pandemic in Sweden. *Scand J Public Health.* 2013 Dec;41(8):853-9.
58. Scherer LD, Shafiq VA, Patel N, Zikmund-Fisher BJ. Can the vaccine adverse event reporting system be used to increase vaccine acceptance and trust?. *Vaccine.* 2016 May 5;34(21):2424-9.
59. Taylor-Clark K, Blendon RJ, Zaslavsky A, Benson J. Confidence in crisis? Understanding trust in government and public attitudes toward mandatory state health powers. *Biosecur Bioterror.* 2005 Jun 1;3(2):138-47.
60. Edmonds BM, Coleman J, Armstrong K, Shea JA. Risk perceptions, worry, or distrust: What drives pregnant women's decisions to accept the H1N1 vaccine?. *Matern Child Health J.* 2011 Nov 1;15(8):1203-9.

61. Wada K, Smith DR. Mistrust surrounding vaccination recommendations by the Japanese government: results from a national survey of working-age individuals. *BMC public health*. 2015 Dec;15(1):426.
62. van der Weerd W, Timmermans DR, Beaujean DJ, Oudhoff J, van Steenberg JE. Monitoring the level of government trust, risk perception and intention of the general public to adopt protective measures during the influenza A (H1N1) pandemic in the Netherlands. *BMC public health*. 2011 Dec;11(1):575.
63. Won TL, Middleman AB, Auslander BA, Short MB. Trust and a school-located immunization program. *J Adolescent Health*. 2015 May 1;56(5):S33-9.
64. Wu AC, Wisler-Sher DJ, Griswold K, Colson E, Shapiro ED, Holmboe ES, Benin AL. Postpartum mothers' attitudes, knowledge, and trust regarding vaccination. *Matern Child Health J*. 2008 Nov 1;12(6):766-73.
65. Brownlie J, Howson A. 'Between the demands of truth and government': Health practitioners, trust and immunisation work. *Soc Sci Med*. 2006 Jan 1;62(2):433-43.
66. Buntun V, Gilding M. Confidence at the expense of trust: The mass adoption of the Human Papillomavirus vaccine in Australia. *Health Sociol Rev*. 2013 Mar 1;22(1):88-97.
67. Harris LM, Chin NP, Fiscella K, Humiston S. Barrier to pneumococcal and influenza vaccinations in Black elderly communities: mistrust. *J Nat Med Assoc*. 2006 Oct;98(10):1678.
68. Hilton S, Petticrew M, Hunt K. Parents' champions vs. vested interests: who do parents believe about MMR? A qualitative study. *BMC Public Health*. 2007 Dec;7(1):42.

69. King C, Leask J. The impact of a vaccine scare on parental views, trust and information needs: a qualitative study in Sydney, Australia. *BMC public health*. 2017 Dec;17(1):106.
70. Senier L. "It's Your Most Precious Thing": Worst- Case Thinking, Trust, and Parental Decision Making about Vaccinations. *Sociological Inq*. 2008 May 1;78(2):207-29.
71. Quinn S, Jamison A, Musa D, Hilyard K, Freimuth V. Exploring the continuum of vaccine hesitancy between African American and white adults: results of a qualitative study. *PLoS currents*. 2016 Dec 29;8.
72. Freimuth VS, Jamison A, Hancock G, Musa D, Hilyard K, Quinn SC. The Role of Risk Perception in Flu Vaccine Behavior among African- American and White Adults in the United States. *Risk Anal*. 2017 Nov 1;37(11):2150-63.
73. Shelton RC, Winkel G, Davis SN, Roberts N, Valdimarsdottir H, Hall SJ, Thompson HS. Validation of the group-based medical mistrust scale among urban black men. *J Gen Intern Med*. 2010 Jun 1;25(6):549-55.
74. Anderson LA, Dedrick RF. Development of the Trust in Physician scale: a measure to assess interpersonal trust in patient-physician relationships. *Psychol Rep*. 1990 Dec;67(3_suppl):1091-100.
75. Shea JA, Micco E, Dean LT, McMurphy S, Schwartz JS, Armstrong K. Development of a revised health care system distrust scale. *J Gen Intern Med*. 2008 Jun 1;23(6):727-32.
76. Ozawa S, Sripad P. How do you measure trust in the health system? A systematic review of the literature. *Soc Sci Med*. 2013 Aug 1;91:10-4.

Table 1: Characteristics of quantitative studies

	Year data collected	Location	Vaccine(s) of focus	Study methodology	Number of participants	Cohort or comparison
Berry, Gold, Ryan, Duszynski & Braynack-Mayer (2012) ^[37]	2011	Australia	Childhood, General	Questionnaire/survey	2002	Cohort
Casiday, Cresswell, Wilson & Panter-brick (2006) ^[38]	2004	United Kingdom	Childhood, MMR	Questionnaire/Survey	996	Comparison
Cheng, Huang, Shaw, Kao & Chueh (2010) ^[39]	2009	Taiwan	Postpartum, Pertussis	Questionnaire/Survey	1207	Comparison
Chuang, Huang, Tseng, Yen & Yang (2015) ^[40]	2014	Taiwan	Adult, Pandemic influenza	Questionnaire/Survey	1745	Cohort
Cooper, Hernandez, Rollins, Akintobi & Mcallister (2017) ^[41]	2014	USA	Adult, HPV	Questionnaire/Survey	1203	Comparison
Das & Das (2003) ^[42]	1998	India	Childhood, General	Questionnaire/Survey	146	Cohort
Fowler, Baggs, Weintraub, Martin, McNeil & Gust (2006) ^[43]	2002-2004	USA	Adult, Anthrax	Questionnaire/Survey	404	Comparison
Freed, Clark, Butchart, Singer, & Davis (2011) ^[44]	2009	USA	Childhood, General	Questionnaire/Survey	1552	Cohort
Freimuth, Jamison, An, Hancoj & Quinn (2017) ^[45]	2015	USA	Adult, Influenza	Questionnaire/Survey	1630	Comparison
Fu, Zimet, Latkin & Joseph (2017) ^[46]	2012-2014	USA	Adolescent, HPV	Questionnaire/Survey	400	Comparison
Gilles et al (2011) ^[47]	2009	Switzerland	Adult, Pandemic Influenza	Questionnaire/Survey	601	Comparison
Grabenstein, Guess, Hartzema, Koch & Konrad (2002) ^[48]	1998	USA	Adult, Influenza	Questionnaire/Survey	2090	Cohort
Kolar, Wheldon, Hernandez, Young, Romero-Daza & Daley (2015) ^[49]	2011	USA	Adult, HPV	Questionnaire/Survey	711	Comparison
Lee, Whetten, Omer, Pan & Salmon (2016) ^[50]	2002-2003	USA	Childhood, General	Questionnaire/Survey	2445	Comparison
Manika, Ball, Stout & Stout (2014) ^[51]	Does not state	USA	Adult, HPV	Questionnaire/Survey	117	Comparison
Marlow, Waller & Wardle	2006	United	Adolescent,	Questionnaire/Survey	684	Comparison

(2007) ^[52]		Kingdom	HPV			
McPhillips, Davis, Marcuse & Taylor (2016) ^[53]	2000	USA	Childhood, Rotavirus	Questionnaire/Survey	558	Cohort
Moran, Frank, Chatterjee, Murphy & Baezconde-Garbanati (2016) ^[54]	Does not state	USA	Childhood, General	Questionnaire/Survey	761	Cohort
Quinn, Jamison, Freimuth, An, Hancock & Musa (2016) ^[55]	2016	USA	Adult, Influenza	Questionnaire/Survey	1643	Comparison
Raude, Fressard, Gautier, Pulcini & Peretti (2016) ^[56]	2013-14	France	Childhood, General	Questionnaire/Survey	1582	Cohort
Ronnerstrand (2013) ^[57]	2009-2010	USA	Adult, Pandemic influenza	Questionnaire/Survey	28 798	Comparison
Scherer, Shaffer, Patel & Zikmund-Fisher (2016) ^[58]	2014	USA	Adolescent, HPV	Experimental	1259	Experimental, comparison
Taylor-Clark, Blendon, Zaslavsky & Benson (2005) ^[59]	2002	USA	Adult, Smallpox	Questionnaire/Survey	1006	Comparison
Tucker-Edmonds, Coleman, Armstrong & Shea (2011) ^[60]	2009	USA	Adult, Pandemic influenza	Questionnaire/Survey	173	Comparison
Wada & Smith (2015) ^[61]	2014	Japan	Undefined	Questionnaire/Survey	3140	Cohort
Weerd, Timmermans, Beaujean, & Oudhoff (2011) ^[62]	2009	The Netherlands	Adult, Pandemic influenza	Questionnaire/Survey	8060	Comparison
Won, Middleman, Auslander & Short (2015) ^[63]	2012-2013	USA	Childhood, General	Experimental	1608 / 844	Experimental, intervention
Wu et al (2008) ^[64]	2003	USA	Childhood, General	Questionnaire/Survey	228	Cohort

Table 2: Characteristics of qualitative studies

	Year data collected	Location	Vaccine(s) of focus	Study methodology	Number of participants	De fo
Brownlie & Howson (2006) ^[65]	1998 and 2001	UK	Childhood, MMR	Focus groups and in-depth interviews	58	HC
Bunton & Gilding (2013) ^[66]	2011	Australia	Adult, HPV	Exploratory workshops	46	Ad
Harris, Chin, Fiscella, Humiston & York	2004-2005	USA	Adult, Influenza	In-depth interviews	20	Ad

(2006) ^[67]						
Hilton, Petticrew, & Hunt (2007) ^[68]	2002-2003	UK	Childhood, MMR	Focus groups	72	Par
King & Leask (2017) ^[69]	2010-2011	Australia	Childhood, Influenza	In-depth interviews	25	Par
Senier & Senier (2016) ^[70]	2004	USA	Childhood, general	In-depth interviews	20	Par
Quinn, Jamison, Musa, Hilyard & Freimuth (2016) ^[71]	2016	USA	Childhood, general	Focus groups	118	Ad An

Table 3: Definitions of trust across reviewed literature

	Trust was not explicitly defined	Hints made towards trust concepts mentioned in the literature	Trust defined through extensive use of trust literature.
Vaccine uptake	Cheng et al (2010) ^[39] Das & Das (2003) ^[42] Fowler et al (2006) ^[43] Fu et al (2017) ^[46] Manika et al (2014) ^[51] Kolar et al (2015) ^[49]	Casiday et al (2006) ^[38] Gilles et al (2011) ^[47] Lee et al (2016) ^[50]	Ronnerstrand (2013) ^[57]
Intention to vaccinate	Marlow et al (2007) ^[52] Scherer et al (2016) ^[58] Tucker-Edmonds et al (2011) ^[60]		Taylor-Clark et al (2006) ^[59] Weerd et al (2011) ^[62] Chuang et al (2015) ^[40]
Predictors of trust in relation to vaccination	Berry et al (2012) ^[37] Cooper et al (2017) ^[41] Freed et al (2011) ^[44] Grabenstein et al (2002) ^[48] Wu et al (2008) ^[64] Moran et al (2015) ^[54]	Won et al (2015) ^[63]	Freimuth et al (2017) ^[45] Quinn, Jamison, Freimuth, An, Hancock & Musa (2016) ^[55]

	Wada & Smith (2015) ^[61]		
HCP intention to recommend vaccine	McPhillips et al (2016) ^[53] Raude et al (2016) ^[56]		
Qualitative research	Harris et al (2006) ^[67]	Hilton, Peticrew & Hunt (2007) ^[68] King & Leask (2017) ^[69]	Brownlie & Howson (2006) ^[65] Bunton & Gilding (2013) ^[66] Senier & Senier (2016) ^[70] Quinn, Jamison, Musa, Hilyard & Freimuth (2016) ^[71]

Table 4: The use of measurement across reviewed quantitative literature

	Measures of trust not reported	Used implicitly defined measures of trust	Used literature-aligned measures of trust	Used literature-informed measures of trust
Vaccine uptake	Das & Das (2003) ^[42] Gilles et al (2011) ^[47] Manika et al (2014) ^[51]	Cheng et al (2010) ^[39] Fowler et al (2006) ^[43] Fu et al (2017) ^[46]	Casiday et al (2006) ^[38]	Lee et al (2016) ^[50]
Intention to vaccinate			Marlow et al (2007) ^[52] Scherer et al (2016) ^[58]	Taylor-Clark et al (2006) ^[59] Weerd et al (2011) ^[62] Chuang et al (2015) ^[40]
Predictors of trust in relation to vaccination	Berry et al (2012) ^[37]	Cooper et al (2017) ^[41] Freed et al (2011) ^[44] Grabenstein et al (2002) ^[48] Moran et al (2015) ^[54] Wada & Smith (2015) ^[61] Quinn, Jamison, Freimuth, An, Hancock	Won et al (2015) ^[63] Wu et al (2008) ^[64]	Freimuth et al (2017) ^[45]

		and Musa (2016) ^[55]		
HCP intention to recommend vaccine		McPhillips et al (2016) ^[53] Raude et al (2016) ^[56]		

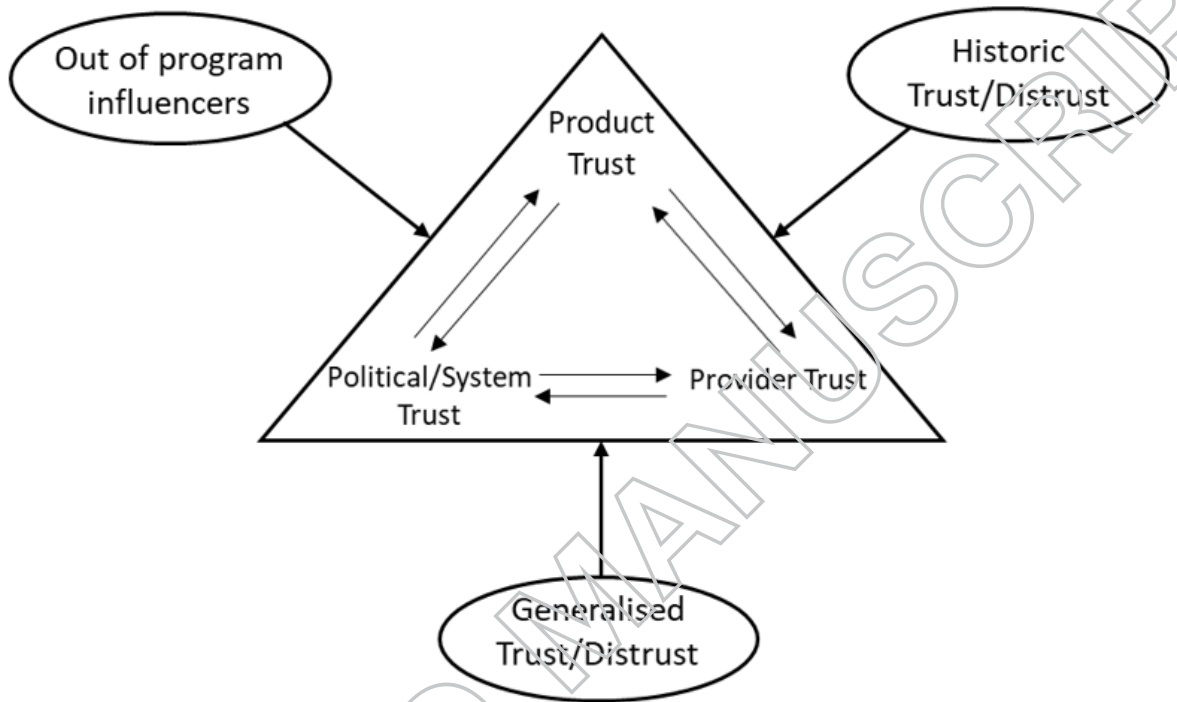


Figure 1: A visualisation of the trust relationships related to vaccination

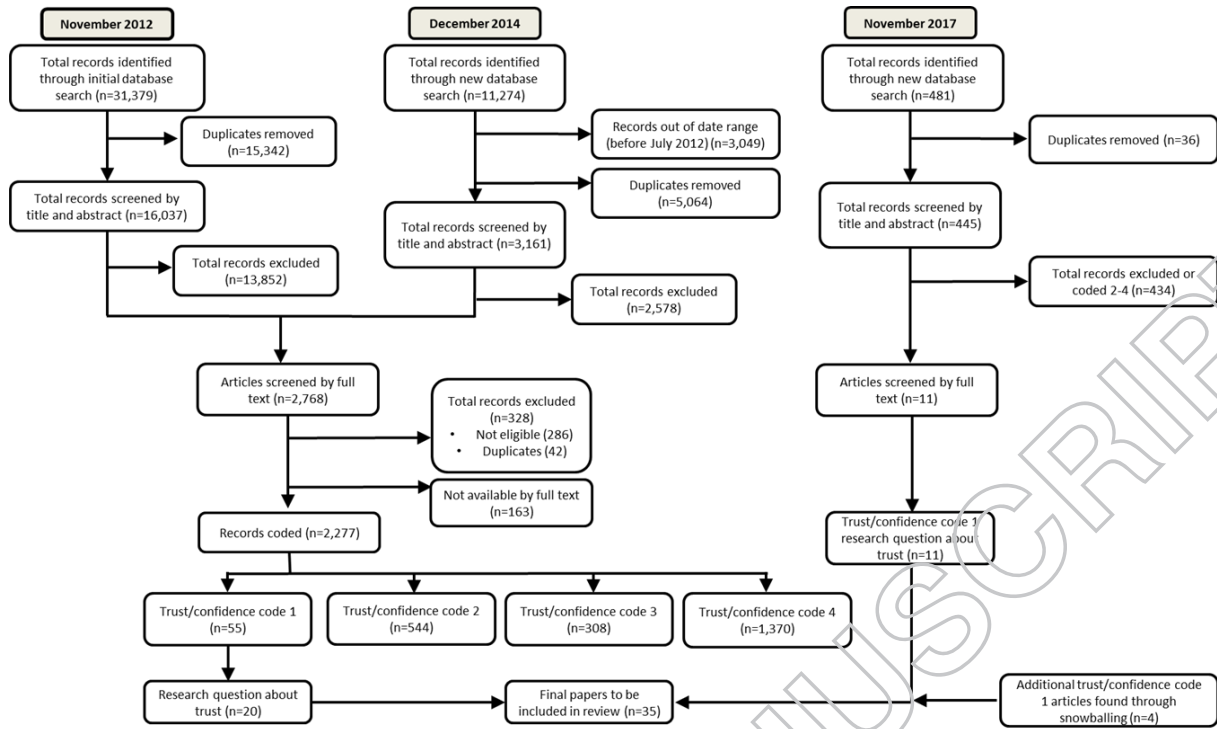


Figure 2: Search flow diagram for systematic review