

# A review and agenda for integrated disease models including social and behavioural factors

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Social and behavioural factors are critical to the emergence, spread and containment of human disease, and are key determinants of the course, duration and outcomes of disease outbreaks. Recent epidemics of Ebola in West Africa and coronavirus disease 2019 (COVID-19) globally have reinforced the importance of developing infectious disease models that better integrate social and behavioural dynamics and theories. Meanwhile, the growth in capacity, coordination and prioritization of social science research and of risk communication and community engagement (RCCE) practice within the current pandemic response provides an opportunity for collaboration among epidemiological modellers, social scientists and RCCE practitioners towards a mutually beneficial research and practice agenda. Here, we provide a review of the current modelling methodologies and describe the challenges and opportunities for integrating them with social science research and RCCE practice. Finally, we set out an agenda for advancing transdisciplinary collaboration for integrated disease modelling and for more robust policy and practice for reducing disease transmission.

ocial and behavioural factors are critical to the emergence, spread and containment of human disease and are key determinants of the course, duration and outcomes of outbreaks. The feasibility and acceptability of adopting recommended health behaviours are intertwined with social, economic, environmental and political complexities that affect individuals, communities and societies<sup>1-4</sup>. Individuals and communities have vital roles in reducing transmission during outbreak response<sup>5</sup> by maintaining preventive behaviours, and actively contributing to response design, implementation and monitoring. Communities and individuals interpret and implement behavioural and other policy recommendations based on factors including their understanding and perception of the disease threat<sup>6</sup>, their level of trust in governing authorities and other information sources, and their physical, financial and social capacity to voluntarily take action7. The design, availability and accessibility of health-related services are bidirectional factors that can increase or reduce the demand for services, in both emergency contexts and routine healthcare settings<sup>8-10</sup>. Despite its importance, individual and community action during outbreaks as well as the factors that influence it are often considered to be distinct from epidemiological trends and biomedical interventions. Such perspectives also pervade the design of disease models.

The field of disease modelling has a considerable and growing influence on vital questions related to public health policy<sup>11</sup>. Large-scale epidemics of new pathogens and global health threats<sup>12-14</sup> (for example, pandemic influenza<sup>15</sup>, Zika<sup>16</sup>, Ebola<sup>17,18</sup> and COVID-19 (ref. <sup>19</sup>)) have underscored the importance of developing models that integrate social and behavioural dynamics and better reflect the realities of affected communities; however, such experiences also highlight substantial challenges<sup>20</sup>. Better incorporation of social and behavioural factors into disease models will probably improve their predictive accuracy and thereby inform more effective response measures and policies<sup>21,22</sup>. Despite the clear need and potential opportunity, progress towards more integrated disease modelling has been slow.

The experience of recent outbreaks has also led to a growing appreciation of, and an investment in, social science research as well as risk communication and community engagement (RCCE)

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interventions as part of response efforts<sup>23–25</sup>. Since the 2014–2016 Ebola outbreak in West Africa, there has been a concerted effort to incorporate social science research and RCCE approaches into traditional response pillars (for example, case management and surveillance)<sup>26,27</sup> through the formation of multidisciplinary response teams<sup>28</sup>. Social science research offers vital sources of social and behavioural data, including quantitative and qualitative data. Similarly, as a central pillar of outbreak response, RCCE interventions can generate real-time reporting of community surveillance data; ongoing qualitative feedback on response measures; and spatial and temporal data for evaluating response interventions. The growth in priority and coordination of social science research and RCCE interventions offers renewed opportunities for collaboration to improve disease modelling.

A review of epidemiological and social science research from the West Africa Ebola outbreak illustrated the comparative advantages of each discipline and the key areas for improvement in terms of collaboration and research design<sup>23</sup>. The review confirmed that disciplinary approaches drove and defined research priorities epidemiological research focused on narrow interpretations of transmission dynamics, associations and outcomes, whereas social science research focused on factors that influence the access, availability and use of services including gender, social roles, vulnerabilities, food insecurity and mobility. Although acknowledged by both epidemiology and social science disciplines, some key public health priorities around social and behavioural factors, such as the roles of funeral practices and community attitudes to disease response, were difficult to adequately quantify in models. This resulted in diverging conclusions regarding the mechanisms that drive transmission and may have undermined decision-making about how to prioritize resources to optimally avert cases. The review also found that epidemiological research drew on broad population (for example, demographic and socioeconomic) data to infer local-level insights; by contrast, social and behavioural research (for example, anthropological studies using individual-level data) often inferred general findings from very small sample sizes. This highlights the trade-offs between local and global information availability<sup>29</sup>. Such divergence in methodological approach and theory reveals biases that are inherent in research priorities and applications that arguably hinder outbreak response decision-making.

To advance a mutually beneficial research and practice agenda, social scientists, RCCE practitioners and disease modellers will require a common framework for understanding and interpreting social, behavioural and operational data and theory. This means that, for modellers, a key goal is to use complex information to develop parsimonious, integrated models that are better designed to capture the factors that underlie observed disease trends compared with models that use traditional sources of epidemiological data alone. For social scientists and RCCE practitioners, more explicit, data-informed modelling of social and behavioural processes (and the extrinsic and intrinsic drivers influencing them) will generate quantitative evidence on the roles and importance of social learning and community action, as well as the impacts of RCCE and other non-pharmaceutical interventions.

#### Modelling social and behavioural factors

Mathematical models have a long history of influencing the scientific understanding of disease epidemiology. Classical disease modelling is based on coupled ordinary differential equations and assumes homogeneous mixing of individuals within a population. This approach has been used for nearly a century, beginning with Kermack, McKendrick, and Walker in 1927<sup>31</sup>. In this simple framework, individuals are in one of the susceptible–infected–recovered states. Importantly, they are assumed not to adapt any behaviour throughout an outbreak<sup>31</sup>. Instead, the dynamics of the model are fully specified at the population level by the number or proportion

of individuals in each disease state. New infections occur with a probability of the density of infectious and susceptible individuals and a per-contact probability of transmission. As such, the classical well-mixed models make the very strong behavioural assumption that contact behaviour is invariant to the prevalence of an infectious disease, analogous to an ideal gas mixing indiscriminately in a chamber. Although this strong assumption is true for some diseases (for example, the common cold) or situations (for example, a boy's boarding school<sup>32</sup>), the history of major epidemics demonstrates that microscale interactions between individuals are important. In practice, observed interactions reflect a range of social, cultural, political, economic and behavioural shifts over the course of a disease; they include both collective and individual behaviours and, most critically, they are dynamic and variable. As such, many commonly used disease modelling approaches (for example, statistical curve fitting models and population-level, compartmental susceptible-infected-recovered models) tend to lack sufficient consideration and mechanistic detail relating to how behaviours mediate or exacerbate transmission, the social nature of behaviour during epidemics, the role of community action and the contextual underpinnings that drive heterogeneity in human action<sup>33–35</sup>.

Systematic reviews by Funk et al.33, Verelst et al.36, Weston et al.37 and Gersovitz<sup>38</sup> considered a broad range of existing disease modelling efforts that account for human behaviour. These reviews emphasize the value of attempts to include social and behavioural parameters in modelling. However, their findings suggest that most model assumptions reflected a limited understanding of the interplay between social and behavioural factors on disease transmission and inconsistently used existing social and behavioural theory and data. These reviews highlight a tendency of models to focus on the economic literature addressing behaviour, or theories adapted from previous modelling papers, rather than theories from psychology or sociology<sup>37</sup>. The use of operational response data is not considered. The models reviewed tended to be theoretical and/or lacked validation against known phenomena or observed data and were therefore unlikely to accurately reflect the complexity and heterogeneity of sociobehavioural drivers and dynamics33.

Nonetheless, existing modelling approaches that attempt to integrate human behaviour offer opportunities to build on methodologies and insights (Table 1). The following section reviews four such modelling approaches.

Economic epidemiology. Economic epidemiologists capture behavioural influence in observed disease dynamics, and vice versa, by introducing the notion of prevalence-elastic behaviour into epidemic models<sup>22,39</sup>. The concept of prevalence-elastic behaviour is used to quantify how population-level infection rates and personal infection status influence the adoption of behavioural recommendations, such as vaccination<sup>22,40,41</sup> and social distancing<sup>42,43</sup>. For example, as the prevalence of sexually transmitted infections grows in a community, people may increase demand for condoms, as occurred during AIDS epidemics44,45; similarly, proximity to disease can increase vaccine acceptance<sup>46</sup>. Economic epidemiologists model how rational individuals (by literal definition) would behave given some level of disease prevalence. They behave as Homo economicus would behave given the associated health risks and costs of protection (for example, isolating and missing work as a result)<sup>47</sup>. The resulting dynamics, termed rational epidemics<sup>48</sup>, capture a clearly important phenomenon: at points during an epidemic at which risk of infection is high, the cost-benefit trade-off shifts in favour of preventative behaviour adoption<sup>49</sup>. By contrast, when infection rates are low, there is less incentive for individuals to adopt health behaviours. Importantly, models that incorporate such prevalence-elastic individual behaviour mechanisms can explain subexponential growth dynamics, including epidemics that exhibit stationary disease dynamics when the susceptible population is large<sup>50</sup>.

Table 1   Summary of fields of work that offer opportunities for integrating social and behavioural factors into mathematical
modelling of disease

modelling of disease				
Field of work	Summary and key features	Challenges to integrating behaviour	Opportunities for integrating behaviour	
Economic epidemiology	Represents changes in individual behaviour as a response to infection/ transmission/economic risk     Considers behavioural change in response to disease prevalence and economic consequences     Accounts for economic and social costs of disease	Assumes that people make rational decisions, contrary to observed decision-making during epidemics     Individual-level focus	•Incorporates endogenous adaptations in behaviour •Inherently multidisciplinary •Can help link disease modelling to the modelling of institutions in group selection and cultural evolution	
Network science	Models disease transmission on realistic structures of human contact patterns     Reflects how behaviour that changes network connections influences disease dynamics	Behaviour based on exogenous parameters (for example, policy) rather than learning occurring endogenously (individual decision-making)	Consider the influence of formal and informal social networks on behavioural change Study the localization of behaviour, misinformation and disease around key subpopulations	
Agent-based modelling	<ul> <li>Captures heterogeneity across population characteristics</li> <li>Generates large-scale patterns, facilitating the design of interventions</li> </ul>	Data and computationally intensive     Difficult to adapt to emergent pathogens if transmission is not well understood	Can incorporate individual, community and institutional behaviour across levels Can reflect temporally and spatially adaptive behaviour Can account for realistic behaviours and contact patterns	
Coupled contagion modelling/ Agent_Zero	<ul> <li>Models the duelling processes of fear and pathogen transmission</li> <li>Cross-disciplinary approach, using principles from psychology and cognitive neuroscience</li> </ul>	●To date, parameterization has been largely theoretical ●Coupled contagions include effects such as fear, but not bounded rationality or network conformity effects	Can consider a range of human needs and influences  Can include social learning data from communities collected in real time during outbreaks  Captures less-rational behaviour	
Social science research	Research of the structural, socioeconomic, environmental and behavioural factors that impact individuals and communities and the transmission of disease Can explain observed epidemiological trends Can identify barriers/enablers to engagement in response interventions	Some data formats may not be directly translatable to mathematical models     May focus on exploratory questions rather than mechanistic research     Challenging to translate findings to action in real time	Can require field-based interactions with the people who are the most affected by the disease Source of context-specific data on behaviour and impact of response measures Existing scientific networks offer mechanisms for initiating more multidisciplinary collaboration in outbreaks	
Community engagement	<ul> <li>Supports communities to mobilize and to identify and address their most pressing issues</li> <li>Mechanism for feedback and accountability to and for communities, response actors and researchers</li> </ul>	Data collection on CE activities is not always systematically captured     Resource-intensive monitoring and evaluation	Source of context-specific data on behaviour and behavioural change at the community level     Can be evaluated as a discrete response intervention     Source of operational data on community interactions	
Risk communication	Exchange of information related to the understanding, assessment, characterization and management of and behavioural responses to risk     Tool for disseminating and collecting real-time information related to individual and community decision-making during outbreaks	change  No feedback loop from information	Source of large-scale, context-specific data on factors influencing behaviour     Can be evaluated as a discrete response intervention     Focus on countering misinformation and disinformation aligns with efforts in network science and ABMs	

Such principles have implications for control strategies in terms of timing and options. Explicit consideration of trade-offs that drive individual decision-making around behaviour adoption enables the evaluation of subsidies, penalties and incentives as interventions<sup>39,40</sup>. Applications of economic epidemiology have been used to investigate trends in the voluntary avoidance of air travel during epidemics of swine flu or A/H1N1 influenza among ticketed passengers<sup>51,52</sup>. They have also been used to consider the economic drivers of

transmission-enhancing behaviours in emerging zoonotic disease systems, as decisions about movement in areas with high interaction with livestock or wildlife often reflect people's consideration of their economic livelihoods<sup>53</sup>. Finally, economic epidemiology models have been used to examine potential externalities from health interventions. For example, measles vaccination can lead to positive externalities through herd immunity (that is, population-level vaccination can prevent measles infection even in those who have

not received the vaccine), whereas negative externalities through the overuse of antibiotics can lead to resistance (that is, individuals not receiving antibiotics can be infected with resistant bacteria and experience treatment failure from the overuse of antibiotics in other individuals)<sup>40</sup>.

Although economic epidemiology offers modelling methods to account for decision-making, we note that human behaviour does not always conform to the canonical definition of rational decision-making whereby agents optimize individual benefit or utility. Affective (and not necessarily conscious) factors, including a range of emotions such as fear and anger, coupled with pervasive errors in appraising risks (including base-rate neglect, framing effects, endowment effects, loss aversion, availability bias and anchoring), all compounded by network conformity effects, can combine to produce behaviours that are far from canonically rational, with far-from-optimal results.

Behavioural change as network dynamics. Modelling disease spread in contact networks provides a representation of the heterogeneity and complexity of human behaviour in the form of the network, or graph, in which an epidemic can occur<sup>54–57</sup>. Top-down interventions affecting contact patterns can be modelled as changes to the network structure<sup>57</sup>, whereas bottom-up behavioural changes are often modelled by coupling an epidemic with the spread of preventative information or behaviours related to the disease<sup>33</sup>. Interventions in this context can be any piece of information (for example, a vaccination campaign or information about transmission risks) that can reduce the risks of transmission. For top-down approaches, the objective of the model is to inform the best targeting strategies, which can be optimized to find highly connected individuals<sup>58</sup>, disconnect social groups<sup>59,60</sup> or be robust to data quality<sup>61</sup>. Bottom-up approaches tend to be more descriptive, often modelled as extensions of classic disease models, assuming random contact within populations and letting disease and information spread and interact<sup>33,62</sup>.

Generalizations exist to account for network structure<sup>63,64</sup>, correlations between physical and information networks<sup>65</sup>, the importance of timing<sup>65,66</sup> and many versions on multilayer networks<sup>67–71</sup>. However, these efforts are largely theoretical as data informing the complexities of human physical and communication networks (and their overlap) are scarce and difficult to collect. Importantly, such efforts also tend to assume a static structure with fixed behaviour, knowledge and contact patterns. Using models of adaptive networks (in which connections between individuals change), one can also study behavioural change as the spread of a pathogen (that is, the dynamics on the network) and of the network structure itself (that is, the dynamics of the network)72-74. Often, individuals in an adaptive network might simply cut or interrupt their contacts with individuals who are infectious<sup>75,76</sup> or reduce the rate of transmission through preventive measures 62,77,78. Beyond this, individuals can also alter the structure of the network itself, replacing infectious contacts—temporarily or permanently—to protect themselves<sup>79–81</sup>. Such models can produce rich dynamics, including increased vaccine effectiveness82, epidemic cycles83, accelerated spread84 and unstable fluctuations in the model<sup>85</sup>. Although learning adaptive behaviour of a population on the basis of empirical data has been considered86, little is known about the social learning behind the adaptive behaviour itself<sup>87,88</sup>. It becomes important to know how to include adaptation as an endogenous behavioural change rather than as an exogenous set of rules. Social science contributions can be impactful here by providing empirically derived insights regarding behavioural change, adaptation, the limits on adaptation and the timeframes over which adaptation occurs in an outbreak scenario7.

Coupled contagion models with an extension to Agent\_Zero. Coupled contagion modelling provides insights into the role of emotions, namely fear, in epidemic dynamics<sup>77</sup>. Specifically, fear

is modeled as a contagion that influences behavioural decisions, which in turn impact disease transmission89. In contrast to the prevalence-elastic behaviour that is characteristic of economic epidemiology models, fear can spread independently from a local prevalence signal (through behavioural contagion), and behavioural responses to fear are not limited to reduced contact (for example, fleeing can increase contact). The essential dynamic is that high disease prevalence induces fear, which in turn produces protective behaviours, such as self-isolation. This distancing suppresses disease spread. However, with reduced incidence, the fear evaporates, and people return to their activities despite the presence of individuals who are infectious in the community. This results in susceptible individuals coming into contact with individuals who are infective, igniting a second wave. This behavioural mechanism was, in part, behind waves of the 1918-1919 pandemic, as well as waves of the present COVID-19 pandemic in many areas. The original model has recently been extended to include two interacting fears: one of disease and one of vaccine, providing yet other behavioural routes to multiple waves of disease.

Whereas fear is considered to be contagious in this model<sup>90</sup>, the cognitive underpinnings of fear acquisition, fear transmission and fear extinction were not explicitly modelled, nor were deliberative biases, heuristics or network effects. These are represented, simply and provisionally, in Epstein's *Agent\_Zero*<sup>91</sup>, 'who' is endowed with affective, deliberative and social modules. Agent\_Zero<sup>91</sup> is a new theoretical entity grounded in contemporary cognitive neuroscience that captures (albeit crudely) some of the well-documented ways in which *Homo sapiens* differs from *Homo economicus*. It is offered as a minimal, cognitively plausible, but mathematically formal alternative to the rational actor.

Although Agent\_Zero has not yet been applied explicitly to disease transmission, it is well-suited to populate agent-based epidemic models with cognitively plausible individuals. The framework is particularly promising to represent collective behaviours such as fear-driven refusal of safe vaccines, or the rejection of mask-wearing and physical distancing measures, which shape disease dynamics. Agent\_Zero's modular framework provides a way to explain such behaviours and, in turn, influence them. The framework can be used to examine the underpinnings of behaviour on the basis of clearly articulated, even if numerous, assumptions. Data-based parameterization will nonetheless depend on experimental findings—absent field studies that can capture relevant information during outbreaks. New methods of sentiment analysis using social media or RCCE data are promising in this regard, as discussed further below.

Agent-based modelling for policy. Individual-level, or agent-based models (ABMs), offer the opportunity to model disease transmission across agents that are representative of the unique, underlying sociodemographic, clinical and other characteristics that make up a population being affected by an outbreak. In an ABM, each individual is explicitly represented, and there is no loss of information due to aggregating or pooling individuals into homogeneous groups. Rather, ABMs can replicate the receptiveness of a heterogeneous community to interventions, such as the use of condoms to prevent transmission of HIV, termination of pregnancies at high risk for congenital Zika syndrome or funeral practices to prevent Ebola transmission.

The technology of ABMs has matured considerably over the last 20 years to the point at which many urban-scale, national-scale and even billion-agent planetary models have been developed and applied to urgent policy problems from smallpox bioterrorism to bird flu, swine flu, Ebola, Zika and the ongoing COVID-19 pandemic<sup>92,93</sup>. Substantial investment—including through the NIH Modelling of Infectious Disease Agent Study (https://midasnetwork.us/)<sup>94</sup>—has led to ABMs providing high-profile contributions to policymaking<sup>15,95-99</sup>.

When informed by sufficient, individual-level data for model parameterization and fitting, and when accompanied by understanding of model limitations, ABMs can be valuable for the design of behavioural interventions. The hallmark of ABMs is that macroscopic patterns emerge 'from the bottom up', from direct agent interactions. Thus, they are laboratories in which we can examine the macro effects of interventions at the microscale or community scale. However, in these frameworks, individual behaviour is sometimes considered in isolation of contextual factors, for example, community-level dynamics or policy-level factors that can influence decision-making.

ABMs can incorporate structurally rich and even dynamic representations of the social or environmental context if designed and adequately parameterized to do so. Mathematically detailed depictions of social network structures or geographical data can be readily included in an ABM-structures that can be challenging to capture in other dynamic modelling approaches<sup>100</sup>. Furthermore, ABMs can include extensive representations of individual adaptation—particularly over longer time horizons—enabling the simulation of the long-term potential impact of any policy or intervention potentially shaped by many adaptive responses<sup>101</sup>. Even on shorter time scales, many of the behaviourally plausible representations of individual responses described elsewhere in this Review require deep engagement with models of adaptation (for example, endogenous changes in individual contact patterns driven by local disease prevalence). Fear is by no means the only emotion that can be modelled102—trust in the medical establishment or in government generally are other such emotions. As in all modelling, gains in insights from the use of ABMs for representing social and behavioural factors will need to be weighed against the number, type and accuracy of input assumptions.

**Opportunities for advancing models.** These modelling approaches integrate social and behavioural data to understand disease spread (Table 1). However, there are clear shortcomings to these approaches that prevent them, in their current forms, from addressing key policy questions, such as those related to healthcare access, availability and use; gender, economic, social, cultural and political contexts; and population mobility, as they relate to disease dynamics<sup>23</sup>.

Why do we find these gaps? There are numerous reasons. First, modellers may understandably have a limited understanding of key social dynamics<sup>103,104</sup>. Second, the lack of robust social, behavioural and operational data means that key dynamics cannot be accurately represented in models without the use of hypothetical scenarios. Third, owing to the complexities of each science, epidemiological modellers may not be familiar with how to use community-level data generated by social sciences<sup>11</sup>, nor how to interpret and apply the wide range of theories about human behaviour and broader sociocultural and systemic dynamics<sup>105</sup>.

### Social science research, RCCE practice

The disciplines that comprise social science research and the operational practices and research related to RCCE are distinct but intimately related. Within the context of epidemic response, they can generate valuable data and evidence (for example, through monitoring and evaluation of RCCE programs, observational studies and the statistical results derived from data) on a range of structural, sociocultural, political, environmental and economic drivers of behaviour affecting disease transmission and engagement with response mechanisms. Social science research and analytics have a critical role in contributing to epidemiological tools, including surveillance or contact tracing, patient intake and line list creation. RCCE approaches support communities to understand new disease threats, interpret and adapt top-down directives, identify community priorities and actions, amplify and replicate community-derived protective actions, and provide essential feedback on response measures.

Efforts have accelerated in recent years to garner a consensus on the essential role of social science research and RCCE practice in understanding and containing disease transmission. This has been in response to well-documented failures within recent outbreaks when such approaches were not adequately prioritized, funded or integrated with biomedical response interventions <sup>106</sup>. For example, initially poor RCCE approaches within the context of the West Africa Ebola outbreak have been identified as having a strong influence on disease transmission <sup>107-109</sup>. Equally, neglect of social science research as a core area of strategic investment in epidemics delayed the establishment of long-term, comparative datasets, structural investments in data collection systems, conventions on data sharing, and the development of key inter-disciplinary partnerships and methodological innovations <sup>23</sup>.

Social science research in epidemic contexts. Social science research during epidemics contributes to an understanding of the longer-term structural and environmental factors and behaviours that impact disease transmission<sup>23,110</sup>. To better understand outbreak dynamics and to inform response strategies and interventions, social science research offers a wide scope of approaches, methodologies and data in support of specific research questions. These generate insights into core epidemic dynamics and how these factors may influence transmission. Such approaches provide context and data for understanding sociocultural trends (for example, mobility, migration, gender and the vulnerability of women<sup>111</sup>, impacts on children<sup>112</sup> and high-risk populations<sup>113</sup>), reluctance or resistance to interventions<sup>114</sup> (for example, trust in governments<sup>115</sup> and institutions<sup>116</sup>), healthcare (for example, access to and availability of health-seeking behaviour<sup>117</sup>), infection and recovery (for example, infection prevention<sup>118</sup>), epidemiology and the public health response (for example, perceived feasibility of preventive measures<sup>7</sup> and mass quarantines<sup>119</sup>). With accelerated research and development of diagnostics, vaccines and therapeutics, evidence from social sciences offers important insights for participatory practices 120,121 with multiple stakeholders and optimizing implementation of clinical research in pandemic contexts<sup>122,123</sup>.

Social science research is often based on analyses undertaken using routine data (for example, quantitative, systematic household or healthcare worker surveys) to measure trends and impacts over time as well as data and evidence gleaned from qualitative methods. In recent years, social science research has generated substantial data on perceptions and behaviours related to outbreaks of Ebola<sup>7,124–126</sup>, Zika<sup>127</sup>, polio<sup>128</sup> and COVID-19 (ref. <sup>129</sup>). The role of social science research during the West Africa and Democratic Republic of the Congo Ebola outbreaks, in particular, has led to more active integration and operationalization of social and behavioural data, including epidemiological and geospatial information, as part of epidemic response<sup>130,131</sup>.

Community engagement. The Minimum Quality Standards and Indicators for Community Engagement (CE) define CE as a "foundational action for working with traditional, community, civil society, government, and opinion groups and leaders; and expanding collective or group roles in addressing the issues that affect their lives. CE empowers social groups and social networks, builds upon local strengths and capacities, and improves local participation, ownership, adaptation, and communication" 132.

Coordinated within broader government-led epidemic responses and often implemented together with local, national and international organizations, CE supports communities to identify and address their most pressing issues. CE is characterized by community-level mobilization and organization through trusted intermediaries, community-generated action planning methodologies<sup>133</sup>, community liaisons for basic services<sup>134</sup>, social protection and redressal, and community/citizen accountability mechanisms

and feedback loops<sup>135</sup>. CE practitioners aim to fully integrate community insights operationally into outbreak response pillars and within government-led response decision-making structures<sup>26</sup> to ensure that these services are responsive to community needs and inputs<sup>132,136</sup>. When undertaken with quality and rigour, CE and participatory leadership can increase the demand for health services<sup>137</sup>, support buy-in for health responses, improve the quality and satisfaction of services, and strengthen health systems<sup>138</sup>.

There has historically been limited standardization of CE, particularly around data collection, to enable evaluation <sup>139,140</sup>. A review conducted by UNICEF identified more than 1,000 distinct CE indicators addressing a broad range of behavioural parameters (UNICEF, available on request). When CE datasets are available, they are often not formally considered for distribution or preservation <sup>141</sup>. They are often decentralized, fragmented and not representative at the population level, and are therefore difficult to compare across countries. Recently, there have been efforts to develop minimum standards for practice and measurement for CE<sup>132</sup>, and better documentation of how evidence can be used to adapt response interventions <sup>131</sup>. When prioritized, standardized and better coordinated to address these methodological and other issues, CE data on a range of behavioural, temporal and spatial parameters can, and has, been collected in real time and at scale during epidemics <sup>142,143</sup>.

Risk communication. Risk Communication (RC) can be generally understood as an iterative exchange of information among individuals, groups and institutions related to the assessment, characterization and management of risk 144,145. It is a cross-cutting tool that aims to provide real-time information to support individual and community decision-making. RC approaches use a range of messaging platforms and methodological approaches, including communication for behavioural change, mass media, social media, health education and health promotion 146.

As a well-developed area of research and practice, RC has evolved to take into consideration subjective and objective risks determined by social, cultural, economic and psychological factors<sup>144</sup>. Real-time and retrospective data and analysis related to RC and associated outcomes has been undertaken within the context of COVID-19 (ref. <sup>147</sup>) and Ebola<sup>148</sup>, including large-scale community feedback data by monitoring rumours during the Ebola outbreak in the Democratic Republic of the Congo <sup>135,149</sup>, as well as tracking digital misinformation during the Zika outbreak <sup>150</sup>, about HIV/AIDS <sup>151</sup> and SARS <sup>152</sup>, and on social media <sup>153–156</sup>.

An integral part of RC involves identifying and countering misinformation and disinformation, the impacts of which can be extreme and immediate<sup>157</sup>. The experience of the COVID-19 epidemic has further highlighted the pernicious nature of misinformation as a risk in itself<sup>158</sup>, and has spurred the emerging field of infodemiology. Infodemiology—the science of understanding how information spreads—will be an important source of data in an age of increased communication and messaging virality<sup>159</sup>. The large volume of information—some accurate, some not—that comes alongside an epidemic is not new<sup>160</sup>, but amplification of the information through social media makes it a much more complex phenomenon to understand and manage. Infodemics can have an impact on health directly by influencing decision-making, and indirectly by promoting stigma, racism and discrimination<sup>161</sup>.

## Challenges and opportunities for a collaborative agenda for integrated modelling

This is not the first call for multidisciplinary dialogue to integrate behavioural determinants into disease modelling <sup>162,163</sup>. The COVID-19 pandemic has underscored the necessity and increased the urgency for such collaboration. Unprecedented attention and advancements in the field of disease modelling offer new opportunities to build on the existing body of work to integrate social and

behavioural parameters. Concurrent growth in the capacity, coordination and prioritization of social science research and RCCE practice also provides opportunities for more meaningful dialogue. The following section outlines the key challenges and opportunities for advancing a collaborative agenda for integrated modelling.

Building a multidisciplinary community of practice and common framework for collaboration. While there is ad hoc collaboration across the disciplines, this is typically unsystematic and opportunistic in nature. There is presently no consistent set of protocols for collaborative research and model design across modelling and social science disciplines, nor a uniform approach to data collection and management. Despite calls for collaboration, there is not a widely shared appreciation of the comparative strengths of different disciplines. Disease modellers generally have a strong understanding of disease epidemiology and transmission dynamics for predicting the course of an epidemic, but less expertise on sociocultural and other non-biological drivers of differential behaviour related to disease transmission. By contrast, social scientists and RCCE practitioners generally use more holistic frameworks, theories and empirical methods to understand concerns, beliefs, assets and actions of individuals and communities that are most affected by disease (including those marginalized within communities) but may lack the tools to quantify the health impacts of social and behavioural interventions or to translate insights into meaningful model inputs. Unpacking these comparative advantages, and aligning on common goals and terms, are the first steps towards developing a community of practice.

Collaboration begins at the conceptualization of research questions about specific behavioural and epidemiological outcomes. Figure 1 presents a schematic of key actors and indicative processes of multidisciplinary participatory disease model design. Such a design process should be responsive to direct input from local communities and simultaneously focused on addressing the data-for-decision needs and priorities of response decision-makers. This includes adequately planning for and addressing ethical concerns related to data collection, transparency, validation of assumptions, unintended consequences, and accountability to communities and research participants <sup>164</sup>. To best operationalize behavioural data in real-time, the disease response architecture itself must be adjusted, for example, by consistently embedding social scientists and RCCE practitioners within epidemiological teams, or by planning for a dedicated, integrated analytics cell.

Developing computationally tractable formulations and validating model assumptions. Mathematical models are necessarily developed with simplifying assumptions. To define research questions that better incorporate social and behavioural factors, new formulations to account for such factors will be required. Modellers must strike a delicate balance, harnessing available data and theory on complex social and behavioural phenomena, while retaining important modelling properties, such as tractability and parsimony. There is ample scope to carefully evaluate modelling assumptions and identify opportunities for improvement.

In present adaptive network models, for example, behavioural reactions to the disease are often selected using an 'Occam's razor' approach—incorporating intuitive mechanisms of which the mathematical form is often chosen for convenience. These models tend to make two large assumptions. First, that information is clearly localized in the network such that individuals mostly react to the state of their direct neighbours or contacts. Second, that the scale of behavioural reactions follows a linear relationship with perceived or actual epidemic risk. However, emerging evidence from research in health psychology<sup>165</sup> shows how social sciences can help to parametrize more realistic models and relax the first assumption. Similarly, behavioural data on individual reactions to local cases of an

#### Multidisciplinary teams contributing domain-specific knowledge and awareness of available data Mathematical RCCF Social **Epidemiologists** Clinicians Communities ABM, network models and coupled contagion Modelling Research approach Sociobehavioural Novel mathematical data gaps formulations Design process Accountability to Epidemiological communities trajectorie Clinical Biological Outcomes Parameters Epidemiological

**Fig. 1** An approach to more integrated modelling. Key to more integrated modelling is multidisciplinary collaboration among epidemiologists, clinicians, social scientists, mathematical modellers, RCCE practioners and members of communities directly affected by disease. Through a design process, the team decides on research questions and modelling frameworks to address the research or programmatic questions. The design process should involve a conscious effort to let questions of the greatest relevance to affected communities and first responders drive decisions about modelling approaches, which may be based on extensions of existing methods or warrant novel formulations. Assessment of the parameters needed with awareness of the data available could generate knowledge about data gaps to be filled through field studies or could result in new mathematical formulations. Explicitly incorporating behaviour would enable assessment of the epidemiological impact of less conventionally investigated interventions, such as RCCE. All outcomes warrant accountability in terms of sharing results with stakeholders and affected communities. The process should be iterative with rigorous testing and validation practices. S, susceptible; E, exposed; I, infected; R, recovered.

infectious disease<sup>166</sup> will help modellers to relax the second assumption to better understand the often-non-linear relationship between behavioural changes (at different depths of one's social circles) and perceived risks associated with the disease. In this way, input from social sciences can lead to better adaptive network models, guided not by mathematical convenience but by a better understanding of the psychology of social and behavioural change.

To improve accuracy and draw correct conclusions, modellers can validate (and adjust) fundamental assumptions about issues such as trust, fear, response efficacy and self-efficacy with social scientists and practitioners who have context-specific expertise and direct links to communities. Core concepts, such as trust in official authorities versus local leaders, are challenging to generalize due to complex sociocultural and political dimensions in different contexts. For example, although there was a frequent assumption among modellers about how fear led to evasion of public health interventions during the West Africa Ebola outbreak, social scientists observed that fear was not unidirectional; there was fear of response authorities in some cases, but there was also fear of the consequences of the disease (for example, of death and infecting family), which motivated people to voluntarily modify their behaviours, including deep-rooted cultural practices<sup>167</sup>. Social constructs also influenced how fear manifested. For example, although families with patients with suspected Ebola were fearful of contracting Ebola, the sense of duty and obligation to care for a family member often prevailed over the underlying fear of becoming infected<sup>168</sup>.

Accessing and making full use of social, behavioural and operational data. In cases in which there is an insufficient availability of

comprehensive data to quantifiably incorporate social and behavioural factors, mathematical models by their very nature depend on simplifying assumptions. Identifying appropriate parameters and incorporating associated essential data—that is, taking complicated, dynamic processes and interpreting them as something that can be incorporated into a mathematical model—is a pervasive challenge<sup>162</sup>.

Nonetheless, there is clearly room to make better use of data that are available, but of which access requires direct outreach and collaboration across the disciplinary divide. For example, one review of the modelling literature found that less than 80% (of 178 articles examined) of studies that sought to incorporate behavioural factors used any empirical data for either parameterization or validation<sup>36</sup>. Another review found that, although 50% (21 out of 42) of studies explicitly used behavioural data sources, these sources were limited to secondary data (for example, survey data cited from previous papers), demographic data and epidemiological data<sup>37</sup>. Modellers can make use of a broader set of available social and behavioural data to achieve more representative selection parameters and validation processes that result in more nuanced and accurate assumptions. Data of different types and sources can be collected as a component of structured CE activities during outbreak response and can in turn be used to model—retrospectively and in real time—the impacts of CE interventions on disease transmission. Large-scale, spatiotemporal mixed CE data (social, behavioural and operational) from Sierra Leone are presently being used to retrospectively investigate contextualized trends in behavioural change during the 2014-2015 Ebola outbreak and to quantify the impacts of CE on behavioural and epidemiological outcomes, including modelling of the

#### Table 2 | Examples of current and potential questions Examples of questions currently addressed by models, categorized by Potential questions around social science and RCCE practice to be modelling approaches reviewed in the main text addressed with the integrated modelling approach •What is the influence of economic factors, disease •What effective RCCE approaches are required for improving adherence epidemiology severity and adaptive behaviour on disease transmission to epidemic control measures? •Which RCCE approaches that combat fear, stigma and mistrust are • How do we design intervention policies that balance most effective for reducing transmission? economic consequences and public health impacts? •How does the type (for example, face-to-face, social media), timing and frequency of health education campaigns impact disease Network science • How do we target interventions to best reduce transmission? •What are relevant, feasible and acceptable approaches to supporting • How do we model superspreading events and the physical and psychosocial needs of those caring for patients? interventions to prevent them? •What are the epidemiological impacts of addressing the needs of ABM •What is the effectiveness of social distancing policies healthcare providers? such as school closures and infection control protocols •What are the epidemiological consequences of pandemic control in healthcare settings on epidemic control? measures that affect the availability, access, use, appropriateness and •What would be the optimal allocation of vaccines quality of health services, and how can these be mitigated or amplified? across sociodemographic groups in the presence of •What are the differential gender impacts of and on an outbreak, and vaccine hesitancy? how are these addressed within an operational response? •What is the quantifiable contribution of household •How do policies that influence healthcare-seeking impact interactions on disease transmission? hospital-originating infections? Coupled contagion • How do existing and new theories of behaviour •What religious or sociodemographic subgroups should be a focus for modelling and influence our ability to mitigate the spread of infectious RCCE interventions to optimize the impact of transmission-reducing Agent\_Zero • How can we leverage emotional responses to infection •How do decisions around behaviour adoption vary across sex, (and theories of behaviour) to mitigate transmission? age and other subgroups, and what are the epidemiological and/or How can we address multigenerational or programmatic implications? •How does the location, timing and frequency of community interaction community-based transmission of ideas surrounding public health interventions (that is, vaccine hesitancy/ with community mobilizers impact disease transmission? refusal)? •What are the impacts on transmission of specific actions prioritized by communities—for example, the establishment of by-laws or community action plans? •How can we determine the quality, efficacy and usefulness of community-generated data compared to more formal, scientific data? •What are the relative efficacies of social science data at different sample sizes (that is, what sample sizes are practical for integrated modelling)?

relationship between CE mobilizer visits and disease transmission, mobility and behavioural change<sup>142</sup>.

Strengthening coordinated collection and consolidation of social and behavioural data. In turn, social scientists and RCCE practitioners can improve the collection of relevant social and behavioural data at sufficient scale and with quality and rigour. Social and behavioural data collection, management, storage, aggregation and sharing within the context of epidemics in real-time can be difficult to perform at scale<sup>162</sup>, but has been shown to be achievable if prioritized and funded<sup>142,169</sup>.

The RCCE Collective Service—a new coordination mechanism led by the WHO, UNICEF and IFRC—has now produced the global COVID-19 RCCE Framework and Core Indicators and a standardized question bank, the first such global, multi-country framework for social and behavioural data collection and RCCE in an outbreak response. This approach and platform represent a meaningful step forwards to enable more systematic cross-country data collection, analysis and synthesis<sup>170</sup>. Similarly, knowledge and data-sharing platforms such as the GOARN-R<sup>171</sup>, Ebola Anthropology Platform (http://www. ebola-anthropology.net) and Social Science in Humanitarian Action Platform (https://www.socialscienceinaction.org) as well as initiatives such as the Sonar-Global Network<sup>172</sup> have also increased the visibility, accessibility and application of social science research. Similarly, the use of digital tools for data collection during the COVID-19 epidemic has offered insights into opportunities for modelling with more granular behaviour data, for example, self-reported mask compliance

from large-scale social media surveys; changes in contact patterns through geocoded cell phone mobility data<sup>173–175</sup>; and tracking and coding sentiments, rumours, and misinformation and disinformation through digital social listening initiatives<sup>176</sup>.

At the community level, disease-specific social and behavioural risk factors can be included in case investigation forms during outbreaks. Although there are examples of these being included previously (for example, burial participation for Ebola investigations<sup>177</sup> and occupational setting for COVID-19 investigations<sup>178</sup>), social and behavioural data elements are usually not included in standard case investigation forms<sup>178</sup>. Retrospective sociobehavioural assessments outside of the case investigation process are relied on much later into the outbreak to understand the role of social and behavioural factors on the epidemiology of the outbreak<sup>179</sup>.

Data collection during outbreak response can be best achieved through the establishment of transdisciplinary teams working together during outbreak response to collect and analyse data. During the Ebola epidemic response in the Democratic Republic of the Congo, the Social Science Analytics Cell established by UNICEF more proactively prioritized data collection and used integrated multidisciplinary outbreak analytics to develop and communicate real-time evidence to explain differential trends in outbreak dynamics, understand changes in health outcomes over time and measure broader health and community impacts of the outbreak <sup>14,180,181</sup>. These examples help to illustrate the potential of both collecting better data to inform models and developing better models to quantify the impact of social and behavioural interventions.

#### Recommendations

Drawing on the comparative advantages and examples detailed above, we offer the following recommendations to advance better integration of social science research and RCCE practice in epidemiological modelling:

- 1. Build a community of practice for networking, partnership-building and collaboration. Testing and learning together using existing models that incorporate simple behavioural mechanisms (such as those described above in "Modelling social and behavioural factors") will enable social scientists and disease modellers to collaborate using observed data to develop models for future application and as part of epidemic preparedness. The community could be its own entity with membership or be a collaborative effort between existing entities that to date have been predominantly focused on social sciences or mathematical modelling.
- Develop protocols for the integration of contextual, sociocultural and behavioural factors into modelling. Establish ethical frameworks, data protections, research protocols and collaboration processes to guide the co-creation of research questions. frameworks, methods and other innovations. Collaboratively designed research questions (Table 2) will lead to more targeted and focused model outcomes, and to more evolved modelling methodologies. Given the vast research resources available from present and past pandemics<sup>182,183</sup>, a key focus should be the testing, calibration and validation of dynamic models that integrate real-time and historical social science evidence in public health emergencies. Focus collaboration on identifying ways to parameterize quantitative and qualitative data, the theories that underpin decision-making processes, along with understanding and incorporating existing historical data on individuals, communities and populations, with respect to social norms, cultural practices, existing 'baseline' political economy and other factors 112,184,185.
- 3. Build or expand on open-source model and code repositories that can focus on integrated disease modelling. All stakeholders would benefit from the availability of existing data, methods, themes, models and software to all stakeholders<sup>186</sup>. A model and code repository would offer a wide range of social science and modelling resources based on present standards of practice and will support more efficient innovation, collaboration, and ongoing iteration and discovery. Existing repositories (such as the CoMSES Net platform for agent-based modelling (https://www.comses.net)) can form the basis of expanded efforts to extend resources to include social science disciplines.
- 4. Develop prepositioned sets of RCCE data frameworks, including thematic priorities, measures and indicators. At the response level, incorporating social, behavioural and community-level data into outbreak investigation protocols will enable the timely collection of data—for example, including data on the adoption of transmission-reducing behaviours and the level of adherence to these, as well as the reasons for refusal or inability to adopt behaviours—that can be mined for insights regarding the potential social and behavioural drivers of an outbreak. Such data can inform the context-varying assumptions and parameterization of integrated disease models in real time during an outbreak.
- 5. Preposition data sharing agreements between researchers, governments and other response actors to facilitate rapid data movement from field-based data collection centres to centres of modelling and research, particularly at the country level whereby findings can be directly applied to response operations in near real time. Disease modellers need better access to social science and RCCE data across platforms and networks. Data, even from small-scale initiatives, can be used to develop and

- test integrated modelling frameworks<sup>187</sup>, even as standards for larger-scale data collection are developed. As the data gap is addressed, more information will improve model formulation and calibration to the contextual realities of disease and behavioural dynamics.
- 6. Establish and sustain transdisciplinary teams to routinely work together during an outbreak response. The institutionalization of cross-pillar coordination and the development of agreed standard operating procedures spanning the administrative, biomedical and RCCE pillars (for example, that undertaken by the Social Science Analytics Cell in the Democratic Republic of the Congo) is needed for integrated analytics become a reality in outbreak response. Working within the established policy contained within international frameworks (such as the International Health Regulations and Emergency Response Framework), the operationalization of on-the-ground collaborations between epidemiologists, social science professionals and practitioners will provide a robust foundation for our recommendations towards integrated modelling.
- Facilitate training and peer exchange to develop mutual understanding and shared skill sets among epidemiologists, modellers, social scientists, RCCE practitioners and decision-makers. Create training opportunities for modellers to acquire a foundational understanding of core theoretical and methodological principles in social sciences and to engage with the complex theoretical bases of behavioural, sociocultural and social sciences research. Social scientists can be trained on the various types and forms of model inputs and frameworks that may be appropriate for investigating social and behavioural questions in epidemic contexts. This might include incorporation into existing graduate programmes, research exchanges between institutions or similar to short courses developed for increasing knowledge across disciplines 188,189. It should be recognized that opportunities for collaboration for researchers in low- and middle-income countries are often inequitable, despite evidence that such access improves research outcomes<sup>190</sup>. Access to research and data, as well as the capacity, resources and opportunities to use this data, are often inequitable and/or underrecognized<sup>191</sup>. A priority focus should be placed on researchers from lower-middle-income countries working in their own contexts.
- 8. Review research undertaken during recent epidemics from the perspectives of epidemiology and social science. Understanding how the respective fields have addressed research questions within specific outbreaks will provide a targeted analysis of broader research themes prioritized by epidemiological and social science research, an improved understanding of the factors and assumptions addressed within these themes, and the identification of areas of complementarity and respective gaps between disciplines from real-world examples. Such reviews can support an understanding of how the research lens applied can result in differing assumptions, findings and recommendations, and encourage a mutual understanding of the limitations and opportunities of the respective disciplines<sup>23</sup>.
- 9. Ensure that restitution to local communities is mainstreamed into modelling practices. To close the gap between modellers, social scientists and RCCE practitioners, serious attention needs to be given to how research outcomes are returned to local communities to form a basis for action. The concept—if not always the systematic practice—of feedback loops is well established within humanitarian response, whereby community-generated data result in a response or action<sup>192</sup>. For example, social science research data can directly inform community engagement and action planning<sup>26</sup>. Although, as we have seen, modelling often uses secondary source data, integrated modelling will bring modellers closer to the communities that they model. When integrated modelling aims to better reflect the realities of

- communities by using community-generated data, the onus is on all researchers to ensure that those communities benefit from the outputs. A comprehensive review should be conducted to examine communication practices within the modelling community to determine how to rapidly, efficiently, thoroughly and realistically revert integrated modelling findings and discoveries to national, regional and local stakeholders.
- 10. Jointly and clearly communicate with policymakers to co-create recommendations for immediate, mid-term and long-term actions. There is often a gap between what decision-makers and policy-makers want from models and what models deliver, due to inherent model uncertainties as well as a poor communication and expectation setting<sup>193</sup>. It is essential to communicate model limitations, while identifying those that can be addressed with additional information. This should involve describing how social and behavioural theories have been included in the modelling, which data or proxies have been used and what the results have demonstrated in light of the original collaborative design process. Communication must be carefully crafted to be interpretable by scientists, policy-makers and the public to avoid misinterpretation or misuse of models and outputs<sup>194-196</sup>.
- 11. Advocate for increased investment in integrated disease modelling. Researchers and policy-makers must engage in joint advocacy to donors and grant-making organizations. This is best performed by developing a collaborative—and fundable—research agenda supported by a clear, evidence-based investment case. A funding gap analysis is urgently needed to determine and address the global capacity demands for multidisciplinary research, including integrated disease modelling. A consortium of champions, drawn from the Community of Practice and representative of the different participants in the integrated modelling process (Fig. 1), should undertake the analysis.

#### Conclusion

Disease modellers, social science professionals and RCCE practitioners share the objectives of reducing preventable mortality and socioeconomic burdens associated with disease transmission and disease response measures. Integrated modelling that better incorporates social and behavioural dynamics will advance predictive accuracy and thereby more effectively guide policy and response measures in service of these objectives. To advance a synergistic research and practice agenda, social scientists, RCCE practitioners and disease modellers should develop a community of practice and develop a common framework for understanding and interpreting, social, behavioural and operational data and theory. Such efforts will support mutually reinforcing calibration and validation of models and social science research, while also providing quantitative insights into the impacts of RCCE interventions. A failure to better integrate modelling can result in divergent policy recommendations, which has practical and ethical implications for disease response. While the inherent complexity of disease modelling that incorporates social and behavioural factors can limit the degree to which community realties can be included, the potential of integrated disease modelling remains to be explored.

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#### **Competing interests**

The authors declare no competing interests.

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